THE DEVELOPMENT OF A CONTEXTUALLY APPROPRIATE MEASURE OF INDIVIDUAL RECOVERY FOR MENTAL HEALTH SERVICE USERS IN A SOUTH AFRICAN CONTEXT

by

Anneliese de Wet

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Supervisor: Dr Chrisma Pretorius

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Declaration

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification. This dissertation includes two original papers accepted for publication in peer-reviewed journals and one unpublished paper. The development and writing of the three papers (accepted for publication and unpublished) were the principal responsibility of myself. The nature of the contributions of my co-author (supervisor) and I on all three papers was the same throughout; I conceptualised and wrote the papers and my co-author gave feedback and suggested changes to the papers. The extent of our respective contributions to all three papers was the same throughout; 80% (myself, as primary author) and 20% (my supervisor, as co-author).

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Anneliese de Wet

Abstract

Mental health is a crucial part of the overall wellbeing of persons. Recovery is increasingly recognised worldwide as an essential approach to mental health. In this study recovery is regarded as personal recovery, a multidimensional construct differing from remission. In high-income countries, the study of recovery has developed and expanded to raise individuals' awareness of, and involvement in, their own recovery and to change mental health services to have a recovery-orientation. With increasing awareness and involvement, and changing orientations, comes the importance to measure individuals' recovery for personal, professional and funding purposes. Individual recovery measurement has increased worldwide. In South Africa, the study of recovery and its measurement is still emerging in a context of great challenges and resource constraints. Thus, this study aimed to contribute to the growing knowledge of recovery in South Africa by exploring the understanding of recovery among service users, carers and service providers, the barriers to, and facilitators of, recovery, and by developing an individual measure of recovery that is appropriate to a South African context. The study employed an exploratory sequential mixed-method design. Exploring the understanding of recovery through 37 interviews and three focus groups with service users, carers and service providers at three tertiary psychiatric hospitals in the Western Cape Province of South Africa, and comparing these results with recovery processes established through other empirical work, yielded dimensions and sub-dimensions of recovery appropriate to the study context, which were formulated into a South African definition of recovery. The dimensions of recovery were closely linked to each other and confirmed the layered, iterative and non-linear nature of the recovery process. Together with the barriers to, and facilitators of, recovery, which were also explored during the interviews and focus groups and indicated how recovery happens (or does not) in the lives of service users, the definition and dimensions of recovery were used to inform the formulation of items

and format of the measure. The items were reduced and format refined through a process of preliminary content validity, which consisted of (a) a Delphi panel of professional experts; (b) cognitive interviews with service users; (c) the matching of items and dimensions by clinical experts; and (d) a readability test. The resultant Measure of Individual Mental Health Recovery for a South African context consists of 38 items. This is the first such measure developed for a South African context and makes it possible for service users, together with carers and direct service providers, to use the results from the administration of the measure as a starting point for discussions about the recovery process for the service user. The measure may also provide recovery-oriented programme implementers with a means to determine how participants are moving along in their recovery to report to funders, either to obtain or retain funding. The emphasis throughout the results on support in various forms as crucial to recovery suggests the appropriate and circumspect development of formal peer support work for South African contexts, which may ultimately be beneficial on many levels.

Keywords: mental health recovery, South Africa, definition, barriers, facilitators, measurement, peer support work

Opsomming

Geestesgesondheid is ‘n deurslaggewende deel van algehele welwees van persone. Herstel (*recovery*) word wêreldwyd toenemend erken as ‘n noodsaaklike geestesgesondheidsbenadering. In hierdie studie word herstel beskou as persoonlike herstel, ‘n multi-dimensionele konstruk anders as remissie. In hoë-inkomste lande het die studie van herstel ontwikkel en uitgebrei om indiwidue se bewustheid van, en betrokkenheid by, hul eie herstel te verhoog en om geestesgesondheidsdienste se benadering tot ‘n herstel-georiënteerde benadering te verander. In die lig van toenemende bewustheid en betrokkenheid, asook veranderende benaderings, is dit belangrik om maniere te vind waarop indiwidue se herstel gemeet kan word vir persoonlike, professionele en befondsingsdoeleindes. Indiwiduele herstelmeting het wêreldwyd toegeneem. In Suid-Afrika is die studie en meting van herstel nog ontluikend, in ‘n konteks van groot uitdagings en hulpbronbeperkinge. Dus was hierdie studie daarop gemik om tot die groeiende kennis oor herstel by te dra, deur die begrip van herstel vir diensgebruikers, versorgers en diensverskaffers, en hindernisse tot en fasiliteerders daarvan te verken, asook ‘n indiwiduele herstelmeetintrument, gepas vir ‘n Suid-Afrikaanse konteks, te ontwikkel. ‘n Verkennende, opeenvolgende gemengde-metode navorsingsontwerp is aangewend. Die verkenning van die begrip van herstel deur 37 onderhoude en drie fokusgroepe met diensgebruikers, versorgers en diensverskaffers by drie tersiêre psigiatriese hospitale in die Wes-Kaapprovinsie, Suid-Afrika, en die vergelyking van die resultate met herstelprosesse wat deur ander empiriese werk ontwikkel is, het studiekonteks-gepaste dimensies en sub-dimensies van herstel opgelewer, wat in ‘n Suid-Afrikaanse definisie van herstel geformuleer is. Die dimensies van herstel was nou verwant en het die laagsgewyse, iteratiewe en nie-liniêre aard van die herstelproses bevestig. Tesame met die hindernisse tot, en fasiliteerders van, herstel, wat ook tydens die onderhoude en fokusgroepe verken is en aangedui het hoe herstel plaasvind (of

nie) in diensgebruikers se lewens, is die definisie en dimensies van herstel gebruik ter inligting van itemformulering en die formaat van die meetinstrument. ‘n Proses van voorlopige inhoudsgeldigheidstoetsing, bestaande uit (a) ‘n Delphi-paneel van professionele deskundiges; (b) kognitiewe onderhoude met diensgebruikers; (c) die oppaar van items en dimensies deur kliniese deskundiges; en (d) ‘n leesbaarheidstoets, is gebruik om items te verminder en die formaat te verfyn. Die gevolglike Meetinstrument van Indiwiduele Geestesgesondheidsherstel vir ‘n Suid-Afrikaanse konteks bestaan uit 38 items. Dit is die eerste sodanige meetinstrument wat vir ‘n Suid-Afrikaans konteks ontwikkel is en maak dit vir diensgebruikers, met versorgers en direkte diensverskaffers, moontlik om die resultate van die meetinstrumentadministrasie te gebruik as ‘n beginpunt vir gesprekke oor die diensgebruiker se herstelproses. Die meetinstrument sou ook ‘n middel kon wees vir implementeerders van herstel-georiënteerde programme om te bepaal hoe deelnemers in hul herstelproses voortbeweeg, om aan befondsers verslag te doen om óf fondse te bekom, óf te behou. Die deurgaanse klem in die resultate op die deurslaggewendheid van verskeie vorme van ondersteuning tot herstel, dui op die nodigheid van die gepaste en omsigtige ontwikkeling van formele portuurondersteuningswerk vir Suid-Afrikaanse kontekste, wat uiteindelik op verskeie vlakke voordele mag inhou.

Sleutelwoorde: geestesgesondheidsherstel, Suid-Afrika, definisie, hindernisse, fasiliteerders, meting, portuurondersteuningswerk

Statement Regarding Scholarships and Manuscripts in the Dissertation

The financial assistance of the National Institute for the Humanities and Social Sciences, in collaboration with the South African Humanities Deans Association, towards this research is hereby acknowledged. Opinions expressed and conclusions arrived at are those of the author and are not necessarily to be attributed to the NIHSS and SAHUDA.

Please take note that manuscript 1 (Chapter 4) and manuscript 2 (Chapter 5) were accepted for publication in *Psychiatric Rehabilitation Journal* and the *International Journal of Social Psychiatry*, respectively. The manuscript presented in Chapters 6 is currently (January 2021) under review. There is some duplication in the dissertation and manuscripts pertaining to the introduction, literature review, methodology, and discussion and conclusion chapters.

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I feel blessed by my family and friends who supported me in doing this work from long before the study started. They shared in my triumphs and my moments of despair all along and carried me through it in their various ways – I am forever grateful to them for cheering me on. I would surely not have been able to complete this work without them holding me.

Lastly, but certainly the most important of all, I thank the participants for taking part and giving of themselves to help make this study what it is. I want to single out the service providers, carers and service users, in particular, who were courageous in sharing their experiences with me, a complete stranger. I salute you. You have enriched my life. I hope this work conveys your immense contribution. It is my heart's desire that this work will mean something to you in your everyday lives, ultimately.

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List of Abbreviations

CBR	Community-based Rehabilitation
CHIME	Connectedness, Hope and optimism about the future, Identity, Meaning in life, and Empowerment
HIV/AIDS	Human immunodeficiency virus/Acquired immunodeficiency syndrome
IMR	Illness Management and Recovery Scales
MARS	Maryland Assessment of Recovery in People with Serious Mental Illness
MHRM	Mental Health Recovery Measure
MIMHR-SA	Measure of Individual Mental Health Recovery for the South African Context
NMHPF	National Mental Health Policy Framework and Strategic Plan (2013 – 2020)
PRI	Psychosis Recovery Inventory
QPR	Questionnaire about the Process of Recovery
RAS	Recovery Assessment Scale
RAS-DS	Recovery Assessment Scale – Domains and Stages
RPI	Recovery Process Inventory
SAMHSA	Substance Abuse and Mental Health Service Administration

SMOG Index	Simple Measure of Gobbledygook Index
STORI	Stages of Recovery Instrument
UK	United Kingdom
USA	United States of America

Chapter 1: Introduction

1.1. Background and introduction to the study

Mental health is a crucial part of the overall wellbeing of persons (Slade, 2009). Recovery is increasingly recognised worldwide as an essential approach to mental health (for example, see Anthony, 1993; Australian Department of Health, 2009; Davidson et al., 2010; Gamieldien et al., 2020; K. S. Jacob, 2015; Moran et al., 2020; Parker, 2012; Schrank & Amering, 2007)

The movement towards mental health recovery in psychiatry began formally when, in the United States of America (USA), their Surgeon-General published its first-ever Report on Mental Health in 1999 (United States Department of Health and Human Services, 1999). In this report, it is stated that, "All services for those with a mental disorder should be consumer oriented and focused on promoting recovery" (Davidson et al., 2010; United States Department of Health and Human Services, 1999, p. 455). The Surgeon-General's report proceeded by declaring that mental health services should not only be aimed at the alleviation of symptoms of mental illness, but also at the "restoration of a meaningful and productive life" (United States Department of Health and Human Services, 1999, p. 455). Definitions of recovery were formulated by Deegan (1988) and Anthony (1993) before the Surgeon-General's Report. Deegan (1988) described recovery primarily as "a new sense of self and of purpose within and beyond the limits of the disability" (p. 11). Anthony (1993, p. 15), in turn, expanded, yet, described recovery similarly as,

> Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the

development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.

These two definitions have subsequently gone on to become seminal in the field of mental health recovery and are now quoted, especially Anthony's (1993) definition, by most recovery scholars to place their work within the field. These definitions make it clear that the focus of recovery in mental health is thus not on symptom relief, but on aspects, amongst others, such as purpose, hope and fulfilment, despite a mental illness. Over time, the understanding of recovery has developed further and been expanded by many scholars. It has also become important to investigate recovery and what recovery means in different contexts, as exemplified in this study.

The change in orientation from the historical, negative view of mental illness with an inevitable downward spiralling progression towards a positive view in which there is hope of the possibility to recover meaning and strive towards potential, prompted the government of the USA to bring about changes to its mental health strategies and policies (United States Department of Health and Human Services, 2003). Other countries' governments, such as those of the United Kingdom (UK), Canada, Australia and New Zealand soon followed suit (Australian Department of Health, 2009; Canadian Mental Health Commission, 2012; New Zealand Mental Health Commission, 2012; United Kingdom Department of Health, 2011). The strategy and policy changes that ensued were aimed at providing for the acknowledgement and inclusion of recovery as a value and principle and the adaptation of the mental health services of these countries to move towards a recovery-orientation. As a result, in these countries, programmes to promote mental health recovery have proliferated and services have been oriented towards recovery. Consequently, in the international context, many measures have been developed, adopted and implemented in order to gauge recovery

(Shanks et al., 2013; Sklar et al., 2013) with measurement taking place largely in two ways, either by measuring individual recovery of mental health service users or by measuring the recovery orientation of mental health systems, services or providers.

More recently, in South Africa, recovery as a concept has also been included in policy documents, such as the National Mental Health Policy Framework and Strategic Plan 2013-2020 (NMHPF) (South African Department of Health, 2013) which states, as one of its objectives, the support of service users and their carers to establish recovery in their communities. In addition, one of the NMHPF's values is recovery and it is amplified by the principle that services should be delivered in such a way as to support service users to be able to return to, or take on roles, in their community, as they choose. The objective, together with the value and principle linked to it, are in line with international conceptualisations of recovery and provide an imperative for public mental health services in South Africa to be recovery-oriented and a motivation for recovery programmes to be established. Some mental health recovery programmes have been developed and implemented in South Africa of late (see, e.g., Bila, 2019; Brooke-Sumner, 2016; The Spring Foundation, n.d.), albeit on a much smaller scale than internationally, to support individual service users' recovery and to foster the recovery-orientation of services. With the inclusion of recovery on a policy level and the development of recovery programmes in South Africa, comes the need to find ways in which recovery can be measured in the South African context. This can be approached, as in other contexts, by two means, namely by measuring the individual recovery of mental health service users, and by measuring the recovery-orientation of systems, services or providers. The focus in this study was on the measurement of the individual recovery of service users, motivated by the rationale for this study which stems from a need that was expressed in the public clinical field in South Africa for a recovery measure that is contextually appropriate and can measure individual recovery in the public mental health context.

The measurement of individual recovery may be necessary or useful for various stakeholders. The measurement may be necessary for mental health services to determine whether the implemented recovery-oriented programmes are successful in contributing to the recovery of service users. The measurement may further be required by funders of recovery-oriented programmes to ascertain whether those programmes which they are funding are achieving outcomes that have been set. A third, and important, group of stakeholders, for which recovery measurement may be useful, is for service users and those persons involved in their care, such as their family (carers) and their specific service providers. For this last group of stakeholders, recovery measurement may be a means by which the service user and/or carers and service providers can engage in conversations about the recovery journey of the service user. Such conversations can help service users, and those involved in their care, in understanding the individual process of recovery and setting future goals for the service user in a collaborative way.

When considering the context within which recovery for service users takes place in South Africa, it is necessary to bear in mind that the South African context is characterised by poverty, insufficient development, inadequate funding and the largely institution-based delivery of public mental health services. These characteristics of the South African context as a whole and the public mental health service specifically, make it challenging to deliver these services effectively and efficiently (N. Jacob, 2015; Kleintjes et al., 2013; Lund et al., 2012; Parker, 2012; Stein, 2014; Sunkel, 2014). Due to the contextual challenges in South Africa, as well as the fact that international understandings of recovery and recovery measures were developed in and for contexts with far greater resources and better funding and more well-developed public health care than the South African context, I did not deem the international understandings of recovery and recovery measures to be appropriate for the South African context. In a search of the literature, I found no locally developed measures to

determine the recovery of individual mental health service users in South Africa. The lack of a contextually appropriate measure of individual recovery for mental health service users in the South African context was therefore the problem that I addressed in this doctoral study. In this study, I attempted the development of the first measure of individual recovery for mental health service users, appropriate to the South African context.

1.2. Research question

The study aimed to explore the following research question:

How can a contextually appropriate individual measure of recovery for mental service users be developed in the South African context?

1.3. Aims and objectives

The overall goal of the study was to develop a contextually appropriate measure of individual recovery for mental health service users in the South African context.

The research objectives in the achievement of the overall goal were as follows:

1. To do a literature review on recovery measures to identify international individual recovery measures that are robust and have an evidence base, and to explore the context and service users for which the measures were developed, in order to develop a contextually appropriate recovery measure and to examine the literature on the South African public mental health service context with the purpose of understanding the context for which the recovery measure would be developed.
2. To conduct interviews and focus group discussions with service users, carers and service providers to gain an understanding of their perceptions and understanding of recovery, and the barriers to, and facilitators of, recovery, in order to inform a recovery definition as a basis for the items that were to be included in the measure that was developed.
3. To develop an individual measure of recovery for the South African context.

4. To test the preliminary validity of the developed recovery measure.

The objectives described followed an iterative process, which means that feedback was presented to role players, such as service users, carers and service providers, by way of focus group discussions for each group of participants to validate the results. To find consensus or a group opinion (as suggested by Landeta, 2006), about the measure items amongst the role players, the Delphi method was employed. The iterative process was to ensure a basic participatory action research approach (Bhana, 2010) and that the final measure would be appropriate for the persons for whom it was developed and who would ultimately be using it.

1.4. Definition of key terms

1.4.1. Recovery

Recovery at the outset of this study was focused on the personal processes of the individual and aligned with the views of recovery by proponents such as Anthony (1993) and Deegan (1988), emphasising the individual and intimate nature of the process of recovery and that meaning-making is an aspect of recovery, but not necessarily an absence of symptoms. However, mental health recovery can mean many different things to different people, in different contexts (see section 2.1.1 in the literature review in Chapter 2). An aspect of this study was to focus on understanding what recovery means in the study context specifically. See the manuscript in Chapter 4 regarding how this was achieved and for the definition of recovery that was developed for the study context.

1.4.2. Service user

In this study *service user* generally refers to a person who makes use of mental health services or who lives their life with a mental illness, being any person who self identifies as such or is identified as such by others, unless specifically otherwise indicated in the

dissertation (see also section 2.1.5. in Chapter 2 for a discussion on public mental health care service users in the South African context, which provides further clarity).

1.4.3. Service provider

Service provider in this study refers to a person who delivers mental health services, such as nurses, occupational therapists, psychologists, social workers and psychiatrists.

1.4.4. Carer

Carer is used in this study to denote a person who provides some form of personal, emotional or financial support to a service user.

1.4.5. Barriers to recovery

Barriers to recovery are those influences in a service user's life which contribute, either fully or partially, to them not being able to participate in their own recovery.

1.4.6. Facilitators of recovery

Facilitators of recovery are those influences in a service user's life which contribute to them being able to participate in their own recovery.

1.4.7. Dimensions of recovery

Dimensions of recovery is used as a term in parts of this dissertation to refer to themes of recovery that were generated from the data, in relation to the development of the measure. The use of the term *dimensions* is not to imply that an exploration for coherence as a structure was performed or that the extent of independence of each was determined. The term is used merely for the sake of convenience within the context of the development of the measure.

1.5. Motivation for publication format

The structure of the study lent itself to the dissertation format consisting of scholarly articles. The study results comprised three main parts, as will be explained below, and a scholarly article was prepared for each part.

Through the dissertation by publication, I could obtain feedback on the study as it progressed, enabling me (and my supervisor) to assess progress earlier than through traditional assessment, where successful progress during the course of the study cannot be obtained in this way. The success of the study in the latter instance is only evident at the end of the study, when the dissertation is assessed by examiners (Frick, 2016). In addition, I had the benefit of feedback from independent manuscript reviewers who are experts in their field. Such feedback effectively meant that I had critical input from several scholars in the field and not the examiners alone. This greatly benefitted my scholarly development and motivated me throughout the study.

I intend to continue work and research in the field of mental health recovery after completing my PhD. As such, the dissertation by publication has assisted in establishing and advancing my standing within the field by making my research more accessible than through a dissertation alone (Frick, 2016). In addition, the probability is increased of obtaining funding for further and future research as well as employment in the field, through professional, quality and relevant scholarly articles published during the course of my PhD research process (Frick, 2016).

My supervisor was included as a co-author on the articles and, as a result, also benefits from the additional publications (Frick, 2016). Except for the benefits to myself and my supervisor, the field of recovery in South Africa potentially stands to benefit from the publication of more scholarly articles on the topic. The study of mental health recovery in South Africa is still in its infancy. Some scholars of standing have published on recovery in South Africa, but there is much room for additional work to be done and disseminated. By publishing from this PhD study, the already existing published body of knowledge on mental health recovery in South Africa is expanded and understanding in the field potentially enhanced.

The focus of the research objectives on the ultimate development of a recovery measure and the coherent flow of the research objectives from one into the next, allowed me to prepare scholarly articles that complemented the research objectives. I conceptualised the articles from the data obtained during the course of the study and in such a way that the articles fell within the ambit of the research objectives. The results of the study comprised three main parts, related to the study objectives, and I prepared a scholarly article for each part.

The first part of the study results related to the perceptions and understanding of recovery in the South African context and resulted in the development of a definition of recovery for the South African context, which informed the development of a measure of recovery for the South African context. These results corresponded with the second study objective in section 1.3. The manuscript prepared from these results forms Chapter 4 in the dissertation.

The next part of the results related to the barriers to and facilitators of recovery. The barriers to and facilitators of recovery were closely linked to one of the themes in the first part of the study results. These results once again corresponded with the second study objective in section 1.3. The manuscript prepared from these results forms Chapter 5 in the dissertation.

The last part of the results related to the development of a measure of individual recovery and the preliminary testing of its content validity. The development of the recovery measure was informed by the first and second part of the study results. The third part of the study results corresponded with the first, third and fourth study objectives in section 1.3. The manuscript prepared from these results forms Chapter 6 in the dissertation.

To summarise, the three parts of the study results built on one another and as such the respective articles linked together to form a whole and were suitable for inclusion as chapters in the dissertation.

I conceptualised and wrote each manuscript. My supervisor's contribution was to give feedback on and suggest changes to the manuscript. I am the first author on all the articles submitted as part of the dissertation.

1.6. Layout of chapters

The dissertation consists of a general introduction to the topic of mental health recovery, an exposition of the research problem, its resultant questions, literature review and theoretical framework, methodology and ethical considerations, followed by the articles and a final evaluative chapter. The articles each form a chapter within the dissertation. The articles are incorporated as follows in the chapter layout for the dissertation:

Chapter 1 – Introduction;

Chapter 2 – Literature review and theoretical framework – A review of relevant mental health recovery literature and the public mental health service context in South Africa as well as my own position and the theoretical framework for the study;

Chapter 3 – Methodology and ethical considerations;

Chapter 4 – Perceptions and understanding of recovery for service users, carers and service providers in the South African context (article);

Chapter 5 – Barriers to and facilitators of mental health recovery in the South African context (article);

Chapter 6 – Development of an individual measure of mental health recovery for the South African context (article);

Chapter 7 – Final evaluative chapter – Summative discussion and conclusion to the study.

In Table 1.1 below, I provide a layout of the chapters with details of the manuscripts and their publication status indicated.

Table 1.1

Layout of Chapters and Publication Status

Chapter	**Topic**	**Publication status**	**Authors and title**
1	Introduction		
2	Literature review and theoretical framework		
3	Methodology		
4	Qualitative study on the perceptions and understanding of mental health recovery in the South African context from the perspective of service users, service providers and carers	Published in the *Psychiatric Rehabilitation Journal* on 24 November 2020 (*PRJ-2019-0279R2*) (initial submission date 25 November 2019)	De Wet, A., & Pretorius, C. Perceptions and understanding of mental health recovery for service users, carers and service providers: A South African perspective
5	Qualitative study on the barriers to, and facilitators of, mental health recovery for service users in the South African context from	Published in the *International Journal of Social Psychiatry* on 13	De Wet, A., & Pretorius, C. From darkness to light: Barriers and

	the perspective of service users, service providers and carers	December 2020 (*ISP-20-0425*) (initial submission date 10 July 2020)	facilitators to mental health recovery in the South African context
6	Development and content validation of an individual mental health recovery measure for the South African context	Under review at *Psychiatry Research* from 13 June 2020 (*PSY_2020_1822*) (initial submission date 08 June 2020)	De Wet, A., & Pretorius, C. Development and content validity of a preliminary version of the Measure of Individual Mental Health Recovery for the South African context
7	Discussion and conclusion		

As an introduction to the study, and particularly to the articles published from the PhD, I submitted a short (955 words) opinion piece (De Wet et al., 2019) to *Perspectives in Public Health* for a special issue on mental health and recovery. This article was published in May 2019. This piece was conceptualised and written by me. The article showcases the recovery work done by The Spring Foundation at Lentegeur Hospital, which was the impetus for my PhD study (De Wet et al., 2019). I am the first author and my supervisor and Dr John Parker, the founder and director of The Spring Foundation and a psychiatrist at Lentegeur Hospital, are co-authors, both of whom provided feedback on the draft of the article before

submission. A copy of this article, together with the permission by the publisher to reproduce the article in this dissertation, published in the University's institutional repository, is attached as Appendix A1.

1.7. Explication of chapters

In Chapter 2, I discuss the literature review pertaining to the study and the theoretical framework of the study. I start by exploring some of the ways in which mental health recovery has come to be understood in the international literature. I also examine recovery in context by looking at certain barriers to, and facilitators of, recovery, after which I proceed to give an overview of the history of modern conceptualisations of recovery, followed by a broad description of the study context, South Africa. I then describe public mental health care service users, recovery and some of the recovery-oriented programmes that exist in South Africa. To conclude the literature review, I investigate the existing instruments to measure recovery, where the measurement of recovery in South Africa currently stands and some issues that might impact thereon. In the theoretical framework, I make my ontological and epistemological position clear and discuss the frameworks that I considered, and justify my ultimate choice of the CHIME framework (Leamy et al., 2011), a framework which includes five recovery processes, namely connectedness, hope and optimism about the future, identity, meaning in life and empowerment, as a theoretical framework for the interpretation of the analysed data in the study.

Chapter 3 provides details of the research methodologies used in the study. I start by describing the aim of the study and the broad process of data collection and analysis. Further, I describe the research design and participant characteristics. I also elaborate in detail on the different steps that were followed during the study. To conclude the chapter, I discuss the ethical considerations related to this study. I also include some results in this chapter. Although the inclusion of results in a methodology chapter is unusual, it is necessary in order

to report coherently on the steps followed in the study, to not omit from the dissertation those additional parts of the results that could not be included in the articles contained in Chapters 4, 5, and 6, due to word limit requirements of the journals to which the manuscripts were submitted, and to avoid parts of the methodology chapter having to be repeated elsewhere with those additional parts of the results.

Chapter 4 contains the manuscript of the article, *Perceptions and understanding of mental health recovery for service users, carers and service providers: A South African perspective*, co-authored by my supervisor and me and published in the journal, *Psychiatric Rehabilitation Journal*. This qualitative article discusses the findings relating to the meaning of mental health recovery, emanating from the interviews and focus group discussions with service users, carers and service providers in the study. We generated seven themes with related sub-themes. From these themes, a definition of recovery for the South African context was formulated to inform a next phase of the study. We also discuss the limitations of the study and recommend directions for future research. (De Wet & Pretorius, 2020b)

Chapter 5 contains the manuscript of the article, *From darkness to light: Barriers and facilitators to mental health recovery in the South African context*, co-authored by my supervisor and me and published in the journal, the *International Journal of Social Psychiatry*. This qualitative manuscript discusses the findings relating to the barriers to, and facilitators of, mental health recovery, emanating from the interviews and focus group discussions with service users, carers and service providers in the study. We generated five themes each for the barriers and facilitators. The need for support was established as a fundamental aspect of all the themes, the themes having converging intrapersonal and external origins. We also discuss the context of the study that provides an understanding for these barriers and facilitators and recommend directions for future research. (De Wet & Pretorius, 2020a).

Chapter 6 contains the manuscript of the article, *Development and content validity of a preliminary version of the Measure of Individual Mental Health Recovery for the South African Context* (MIMHR-SA), co-authored by my supervisor and me. This methodological mixed-method manuscript reports on the development and testing of content validity of a preliminary version of a recovery measure for the South African context. The testing of the content validity of this first version of the measure was conducted by using a Delphi panel of professional experts, cognitive interviews with service users as experts by experience, matching of items and dimensions by professional experts and a readability test. The MIMHR-SA was the end result of this process. Challenges encountered in the process of development in the context of the study and recommendations to other researchers embarking on such a process are also discussed.

Chapter 7, containing the summative discussion and conclusion of the study, draws together and integrates the three preceding chapters and associated manuscripts coherently, in order to bind the dissertation as a whole. The perceptions and understanding of, as well as the barriers to, and facilitators of, recovery, as identified by participants, are linked to the development of the definition and measure of recovery for the study context. I also elucidate the scientific contribution of the study and reflect on my experiences as a researcher in the study. This chapter concludes with the limitations of the study, the implications and contributions for practice and recommendations, and my concluding remarks.

Chapter 2: Literature review and theoretical framework

2.1. Literature review

In this chapter I report on my review of the literature relevant to this study and the theoretical framework of the study.

In the initial section of the literature review I explore some of the ways in which mental health recovery has come to be understood in the international literature. I do so by drawing a distinction between personal and clinical recovery, with its related construct remission, as well as between personal recovery and rehabilitation concepts. I also describe psychological, functional, social and relational recovery. Thereafter, resilience is explored as a concept related to recovery. Personal recovery, being the version of recovery with which I align myself most, and which forms the basis for my approach in this study, is examined in more detail to conclude this section. Next, as a continued examination of recovery in context, I discuss barriers to, and facilitators of, recovery. I proceed to give an overview of the history of modern conceptualisations of recovery, followed by a broad description of the study context, South Africa. I then describe public mental health care service users, recovery and some of the recovery-oriented programmes that exist in South Africa. To conclude the literature review, I investigate the existing instruments of recovery measurement and where the measurement of recovery in South Africa currently stands and some issues that might impact thereon.

In the theoretical framework, I make my ontological and epistemological position clear and discuss the frameworks that I considered and which justify my ultimate choice of the CHIME framework (Leamy et al., 2011) as a theoretical framework for the interpretation of the analysed data in the study.

2.1.1. What is mental health recovery?

When exploring what mental health recovery is, it is necessary to emphasise that recovery is concerned with the wellbeing of persons, which can include psychological, relational, social, functional, contextual wellbeing. Although clinical statistics are certainly not central to the recovery literature, it may be useful to give an indication of what the challenges are within the mental health field by citing some basic statistics on the global burden on mental illness. These statistics give one an appreciation of the importance of recovery work not only in the lives of individuals, but also in the clinical field. The global burden of mental illness, measured in disability-adjusted life-years, is believed to be as much as 13% (Vigo et al., 2016). In the global burden of disease rankings, schizophrenia, major depressive disorder and bipolar mood disorder rank among the top 20 diseases (Vigo et al., 2016). These figures identify mental illness as a significant aspect of the global burden of disease, indicating that every effort is required to address this; I regard recovery, in its various forms, as making an essential contribution to these efforts.

In the 1990s, Corrigan et al. (1999) referred to recovery as a "vision for severe mental illness" (p. 1). Subsequently, the meaning of recovery has been expanded, and no longer exists as the vision of a few early scholars (Anthony, 1993; Deegan, 1988), but is rather conceptualised by various scholars. Silverstein and Bellack (2008) do call attention to the fact that some of the early recovery literature was unclear and created much confusion as to how recovery should be defined. Fortunately, much progress has been made in defining recovery more clearly (Leonhardt et al., 2017). Here I set out what the various existing meanings of recovery are as a foundation for exploring the understanding of recovery in the South African context by the participants in this study.

Recovery is a construct with a variety of meanings, depending on the particular view on mental health and how it should be addressed or approached. Two broad schools of

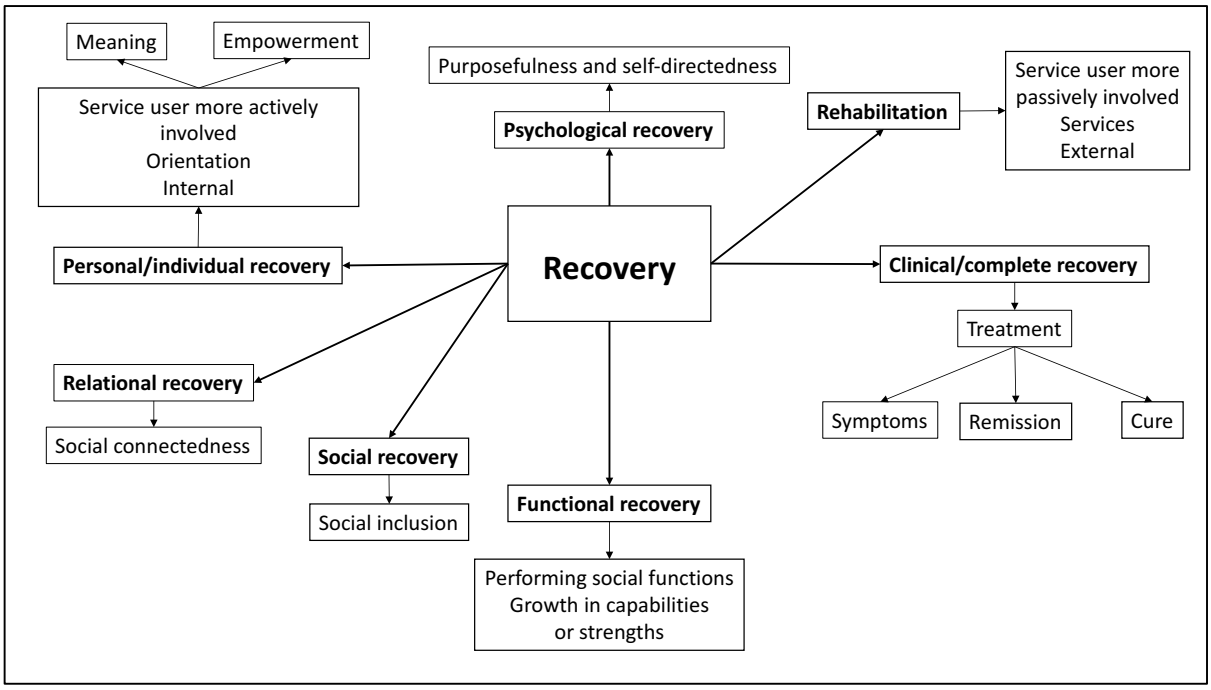
thought on recovery can be distinguished, namely, clinical and personal recovery (Slade, 2009; Slade et al., 2008). The first is concentrated around clinical or complete recovery, where the focus is more on treating mental illness, symptoms, remission of such symptoms and outcomes, with words such as *cure* being used (Slade et al., 2008). In clinical recovery, the biomedical model is the approach by which improvement is attained. The other school of thought centres around personal or individual recovery, which emphasises understanding the experience of mental health for individuals and regards recovery as an ongoing process with or without symptoms, with words such as *meaning* and *empowerment* being used (Deegan, 1988; Price-Robertson et al., 2017; Silverstein & Bellack, 2008; Slade et al., 2008).

In between these two divergent views on recovery, some other meanings of, or related constructs to, recovery exist, such as rehabilitation, functional recovery, social recovery, relational recovery and psychological recovery, which fall somewhere on the continuum of the understanding of recovery.

Figure 2.1 provides a visual overview of some of the meanings of, and constructs related to, recovery that will be discussed in more depth in the remainder of this section.

Figure 2.1

The Various Meanings of, and Related Constructs to, Recovery



2.1.1.1. The distinction between personal and clinical recovery and remission

In the first instance, I examine the distinction between personal recovery and clinical recovery, and its related concept remission, in more depth.

As stated before, and according to Slade et al. (2008), clinical recovery is equated to remission and cure, whereas personal recovery is equated with the living of a fulfilling life despite the persistence of symptoms of mental illness (Deegan, 1988). Clinical recovery is concerned with symptoms, amongst other aspects, whereas personal recovery may include a concern with symptoms, but is more focussed on the relationship the person has with their symptoms (Slade, 2009). The fact that the emphasis on clinical recovery may be beneficial to some service users, whereas it may in fact be harmful to others, is what motivates Slade (2009) to urge service providers to place the emphasis on personal recovery in their services. Slade et al. (2008) make a crucial point when they state that clinical recovery is characterised

by invariance for different service users. It is understandable that, from a clinical or biomedical perspective, recovery would need to be regarded as invariable (Slade, Adams, O'Hagan, 2012), because invariability offers the possibility of operationalising the construct of recovery in a way that is valid for all circumstances and individuals and creates a strict scientific operationalisation that is generalisable and understood across the board in the clinical field, creating little confusion or doubt. However, whether recovery is understood as invariant or not for different service users, is one of the most important distinctions between clinical and personal recovery. Personal recovery, as opposed to clinical recovery, is particularly characterised by the fact that it is "deeply personal", as described by Anthony (1993, p. 15). The uniqueness of the recovery process (Anthony, 1993) is what further sets personal recovery apart from clinical recovery. Importantly, the uniqueness and individuality of personal recovery acknowledges the service user's own experience, which acknowledgement ultimately contributes to the recovery process and indicates a respect for and dignity afforded to the service user and emphasises agency of the service user as well as their empowerment.

The fact that personal recovery is regarded as possible despite the presence of symptoms of mental illness indicates even further that personal recovery can be regarded as distinct from not only clinical recovery, but also remission. According to the criteria set by the Remission in Schizophrenia Working Group in 2005, for remission to occur, symptoms can, at most, be mild and should not have an impact on the way in which an individual conducts herself or himself (Emsley et al., 2011). Harvey (2008) reports that remission is an absence of symptoms or a regaining of pre-illness abilities. Recovery is described as "a more complex concept" than remission by Emsley et al. (2011, p. 117) and as a "higher level of improvement than remission" by Young-Walker et al. (2012, pp. 438–439). From the biomedical point of view (Emsley et al., 2011), remission is regarded as an aspect of

recovery. Young-Walker et al. (2012) regard recovery as "full improvement" (p. 439), which includes symptom remission and functional improvement in work and social domains for a period of two years. This is not the view of those who are proponents of personal recovery. The biomedical view of recovery is explained by Schrank and Amering (2007), Slade (2009) and Slade et al. (2008), as distinct from personal recovery. The biomedical view is not necessarily shared by recovery scholars who advocate for personal recovery and who tend, in varying degrees, to avoid creating a link between recovery and remission (Anthony, 1993; Deegan, 1988). The view of recovery as a remission of symptoms might be practically relevant to traditional psychiatry clinicians, who are proponents of clinical recovery, or those persons who have either had mild mental illness symptoms or do not experience, for instance, more than one psychotic episode. But, for persons challenged by mental illness, the focus of recovery is predominantly on living a life with meaning, despite symptoms. Regardless of this focus on meaning despite symptoms in recovery, an Australian review of the peer-reviewed published recovery literature (S. Jacob et al., 2017) found that although many service users conceptualise recovery as a personal process of change, often service users themselves define recovery by referring to illness, symptom absence or restoration of good health. Chandler et al. (2013) concur, stating that many service users still regard the medical aspects of recovery as important to them in their recovery journey. Because of these varying views of recovery by service users themselves, S. Jacob et al. (2017) repeat the advice of Piat et al. (2017) that harmony should be sought between the personal and clinical views of recovery. Service providers should be adaptable when dealing with service users' varying opinions regarding recovery and when responding to service users' individual recovery needs (S. Jacob et al., 2017; Lloyd et al., 2008). This requires service providers to have a broad definition of recovery, which in turn requires them to be open to, and accepting of, differing views in general and to acknowledge recovery, first and foremost, in its various forms (Lloyd

et al., 2008). Yet, often, circumstances such as scarcity of resources and a high demand on the limited resources that do exist, for instance housing and support, upon discharge undermine such service providers' attitudes (S. Jacob et al., 2017) and consequently the recovery process for individual service users (Onken et al., 2007). In the South African setting one is often confronted by such limited resources, especially in the public health sector, which may thwart the efforts of service providers with a recovery orientation.

2.1.1.2. The distinction between personal recovery and rehabilitation

Another important distinction is that between personal recovery and rehabilitation (Lloyd et al., 2008). Recovery and rehabilitation are often closely positioned in the literature, but there are subtle differences in approach (Slade, 2009). For purposes of discussion of this distinction, rehabilitation includes psychosocial rehabilitation (Brooke-Sumner et al., 2016; Farkas, 1996) and psychiatric rehabilitation (Psychiatric Rehabilitation Association, 2020), these terms often being used interchangeably in the literature, as well as community-based rehabilitation (CBR) (CBR Education and Training for Empowerment, 2015; M'kumbuzi & Myezwa, 2016) and asset-based community development (Haines, 2015). These forms of rehabilitation revolve around service provision to service users and addressing needs on various levels, such as employment and socially. The focus on service provision and addressing needs makes rehabilitation more externally-focused, with service users being more passively involved than those oriented towards personal recovery (Deegan, 1988). Rehabilitation refers to various kinds of support offered to persons with disabilities, whereas recovery refers to the individual's own involvement in the process of coming to terms with their disability (Deegan, 1988; Lloyd et al., 2008; Slade, 2009). According to this distinction, recovery can be regarded as an active involvement, as opposed to rehabilitation that refers to a more passive involvement in coming to terms with one's mental illness (Anthony, 1991, as

cited in Anthony, 1993). It is important to note that rehabilitation approaches are recognised as an aide in promoting recovery (Slade, 2009).

2.1.1.3. Psychological recovery

Andresen et al. (2003) distinguish between what they refer to as medical (related to medical treatment and cure of mental illness), rehabilitative (related to services supportive to living within the restrictions of mental illness) and empowerment (related to healing from mental illness; in the extreme, no need for clinical intervention) recovery. They proceed to conceptualise a definition of recovery, which they call psychological recovery and which they regard as falling somewhere between rehabilitative and empowerment recovery and define neatly as "establishment of a fulfilling, meaningful life and a positive sense of identity founded on hopefulness and self-determination" (p. 2). This may be closely related to other scholars' conceptualisation of personal recovery (Anthony, 1993; Deegan, 1988; Slade, 2009).

2.1.1.4. Functional recovery

Functional recovery is focused on behaviour, which includes how a service user performs various functions daily at home, work or study, and in social situations (Swildens et al., 2018) and is interested in the growth of the service user's capabilities and strengths. Discussions about this form of recovery need to take place from early in the recovery process, according to Lloyd et al. (2008).

2.1.1.5. Social recovery

Social relationships and social contexts can be salient factors in recovery (Lloyd et al., 2008). Mezzina et al. (2006) emphasise the importance of the social aspects of recovery and advise that individuals in recovery should have various naturalistic, as opposed to mental health setting, options when it comes to being included socially. This helps to give the individual service user more choice and a greater sense of self and agency as well as a greater

possibility of a feeling of belonging (Mezzina et al., 2006). Social recovery thus concerns itself with facets of social inclusion of the individual and is closely related to functional recovery (Marino, 2015). Mental health services could also play an important function in engaging service users in social recovery (Lloyd et al., 2008).

2.1.1.6. Relational recovery

Another form of recovery, closely related to social recovery, namely relational recovery, has more recently been posited, and advocates for a move away from the initial individualistic approach of personal recovery towards an approach that foregrounds aspects of relatedness of the individual in their recovery process (Price-Robertson et al., 2017).

2.1.1.7. Resilience and recovery

Schrank and Amering (2007) closely link personal recovery to resilience and consider that the two concepts go hand in hand. Resilience-building has also been regarded as part of recovery (K. Jacob, 2015). Schrank and Amering (2007) recognise a range of abilities as components of resilience, namely the power to withstand challenges, elasticity, recovering original psychological resources, as well as coming through adverse circumstances with additional skills and being stronger and better equipped, with more resources.

2.1.1.8. Personal recovery

In the early recovery literature, personal recovery was described as the living of a fulfilling life despite the symptoms of mental illness persisting (Deegan, 1988). O'Hagan's (2001) definition of recovery, which is succinct and concurs with Deegan (1988), is "to live well in the presence or absence of one's mental illness" (p. 1). The most widely cited definition of personal recovery, according to Slade (2009), is that of Anthony (1993),

> Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the

> development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness. (p. 15)

In his definition, Anthony (1993) emphasises, like Deegan (1988) before him and O'Hagan (2001) after him, that recovery can be achieved apart from remission. Lloyd et al. (2008) concur with this view. These definitions also call attention to the fact that recovery represents an approach to how the individual chooses to live their life (Anthony, 1993) and meaning-making (Anthony, 1993; Leonhardt et al., 2017). Meaning can be, as Jacobson and Curtis (2000) put it, social, political, work-related or spiritual.

In more recent years, according to the Substance Abuse and Mental Health Services Administration (SAMHSA), who do much work in the field of personal recovery in the USA, recovery is defined as "a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential" (SAMHSA, n.d., p. 3). This change process occurs within four "dimensions" (or spheres), namely, "health", "home", "purpose" and "community" and 10, so-called, "guiding principles" (or what I would preferably call, given the other descriptions of recovery in the literature, dimensions and characteristics), namely "hope, person-driven, many pathways, holistic, peer support, relational, culture, addresses trauma, strengths/responsibility and respect" (SAMHSA, n.d., pp. 3–4). The recovery definition of SAMHSA is a combined definition that is used in the field of mental health and substance use. Once again, Anthony (1993), Deegan (1988) and O'Hagan's (2001) views on recovery are re-iterated in the SAMHSA definition.

The historical roots of recovery in the consumer movement gave rise to its original activist nature, led by service users, and the entrenched philosophy behind recovery, that persons should be in control of, and are the experts in, their own lives (Chamberlin, 1990; Deegan, 1992). As a result, the advancement of recovery in research remains linked to user-

led research. However, criticism, especially in the United Kingdom, that has been expressed by researchers, at the forefront of user-led research, towards the personal recovery movement and research. Service user researchers, criticise, amongst other things, what is called the move to "normalisation" (p. 217) of service users in recovery care, the individual nature of recovery (regarding it rather as a social process) and the challenging conditions under which peer support workers perform their roles (Rose, 2014). Detrimental contexts, such as poverty, racial inequality and male-domination, in which many service users have to recover are regarded by critics of personal recovery as by enlarge contributing to service users' inability to attain the goals, that are set for them by proponents of personal recovery and recovery-oriented mental health services, and, consequently, to recover (Rose (2018). Professionals, such as clinicians, involving themselves, with good intention, in the personal recovery movement to bring the spirit of recovery into their approach with service users and within services, have also been criticised for shifting the movement from an activist, user-led movement to something labelled "professional recovery" (p. 1235), performed by clinicians, which distracted from the initial social justice nature of recovery (Hunt & Resnick, 2015).

A scoping review on the meaning of recovery in the context of serious mental illness in low- and middle-income countries, which is currently underway (Gamieldien et al., 2020), will surely also contribute to a deeper understanding of recovery in the South African context.

Although I align myself with the personal recovery approach to recovery and applied it as my personal approach to, and philosophy about, participants in this study, I was aware that I needed to take a broader view on recovery for purposes of this study, especially as one of the research objectives in this study was to gain an understanding of participants' perceptions and understanding of recovery. I maintained awareness of the fact that many

different meanings could be ascribed to recovery and that meanings differing from my own could emanate from the participants' contributions through the data collection process.

2.1.1.9. Characteristics of personal recovery

Exploring the characteristics of personal recovery provides a further richness to the understanding and grasp of the uniqueness and complexity of recovery evident in the literature.

Recovery can be regarded as an outcome as well as a process (Emsley et al., 2011). Leonhardt et al. (2017) also refer to this distinction, namely, recovery as "a subjective process" or "an objective outcome" (p. 1118) in their article focussing on a review of the mental health recovery literature. The view of recovery solely as an outcome tends to emanate from a biomedical point of view (Emsley et al., 2011; Liberman & Kopelowicz, 2002) and focusses on symptom reduction and regaining of functioning (Slopen & Corrigan, 2005). Schrank and Amering (2007) refer to this as the "symptom-focused definition of recovery" (p. 45). Viewing recovery solely as an outcome indicates an understanding of recovery as an achievement. Alternatively, viewed as a process, recovery is not seen as an achievement, but rather an ongoing journey (Parker, 2014b; Slopen & Corrigan, 2005), that may contain elements of outcome. Most recovery scholars would agree with the latter perspective (Deegan, 1988; K. Jacob, 2015; Ramon et al., 2007). Regarding recovery as a process means that recovery is not in the first instance a concern with alleviation of symptoms, but with the leading of a life characterised by purpose and meaning (S. Jacob et al., 2017; Ramon et al., 2007; Schrank & Amering, 2007), whatever that purpose and meaning may be for the individual. Schrank and Amering (2007) call this view the "person-centred definition of recovery" (p.46) and Chandler et al. (2013) echo this view. This view of recovery also addresses the important issue of an ongoing distinction between the general population and the so-called psychiatric population (K. Jacob, 2015; Leader, 2012; Parker,

2014b). When recovery is seen as the movement towards leading a meaningful life of purpose, regarding the journey of service users as the same pursuit as the journey of any person in the general population becomes possible since all human beings are in pursuit of meaning and purpose in one way or another (Parker, 2014b). As Spaniol (1991) states, "Recovery is a process all people experience at some level, at various times in their life" (p. 1). When recovery is viewed as something that we all pursue in various forms, recovery becomes a process integral to the whole person, not specific to an illness (Parker, 2014b), thus making the experience of recovery a universal one.

In addition to recovery being viewed as a process, the process of recovery is also regarded as non-linear (Anthony, 1993; Deegan, 1988; K. Jacob, 2015). As a result of this view, Deegan (1988) warns against rigid programmes aimed at recovery that require service users to progress through the programme in a very linear fashion. More often than not the progress of a service user's recovery involves progress, setbacks, further progress and perhaps even further setbacks, so linear approaches may not necessarily be conducive to the recovery process.

Ralph (2000) reiterates what Anthony (1993) said about recovery, when she regards recovery as the forging of a new way of life following the onset of mental illness, rather than a return to pre-morbid functioning.

Jacobson and Greenley (2001) contribute an important aspect to the understanding of recovery when they view recovery as consisting of both internal factors related to the individual's own process of recovery, i.e., lived experience and inclinations, as well as external factors oriented towards, and thus conducive to, recovery, i.e., environment, services and policies. In promoting recovery, both these internal and external factors must be addressed and supported. In this study, although the focus is rather on these so-called internal

factors, the importance of the external factors, such as the recovery-orientation of services, are acknowledged and highlighted in the recommendations for future research.

2.1.1.10. Dimensions of personal recovery

Having defined recovery more clearly and explored the characteristics of recovery, the dimensions of recovery that have been developed by scholars in the field need consideration in order to complete the understanding of recovery. Jacobson and Greenley (2001) regard hope (possibility of recovery), empowerment (self-determination, fearlessness and taking charge ("responsibility") (p. 483), healing (self separated from disease and control) and connection (social involvement and as a bridge between internal and external factors) as dimensions of recovery. Davidson et al. (2005) also identified certain aspects or dimensions of recovery as "renewing hope and commitment" (p. 484), re-determining identity, acceptance of the mental illness, involvement in purposeful pursuits, overcoming discrimination, gaining control, empowerment and handling of symptoms. Chandler et al. (2013) refer to so-called "key themes" (p. 8) of recovery that are common to persons experiencing mental health challenges. These themes are "hope", "agency" and "opportunity" (p. 8). Andresen et al. (2003) also contributed to the dimensions of recovery by identifying so-called "component processes" (p. 589) of recovery, namely hope, self-identity, meaning in life and responsibility. Farkas (2007) recognised "four key values" (p. 71) that provide support to service users on their recovery journey. These values are: a focus on the service user, the inclusion of the service user in decision-making about themselves and even the delivery of services to others, providing the option of choice to service users, and hope.

From the various characteristics and dimensions of personal recovery that have been put forward by scholars, it is clear that much overlap exists. Leamy et al. (2011), a team of researchers at King's College London, conducted a systematic review and narrative synthesis of the personal recovery literature, incorporating pre-existing models of recovery. From their

findings, Leamy et al. (2011) developed a conceptual framework consisting of 13 characteristics of recovery, five recovery processes and stages of recovery. The 13 characteristics are that recovery can be an active, unique and non-linear process and that recovery can be a journey, can have stages or phases and can be a battle. Furthermore, recovery can be multi-dimensional, gradual, and life-changing. Recovery may also exist without cure, can be advanced through conditions that are characterised by support and healing, may not necessarily require the involvement of professionals and can be an iterative process. CHIME is an acronym for "connectedness", "hope and optimism about the future", "identity", "meaning in life", and "empowerment" (p. 448), these being the concepts identified as "recovery processes" (p. 448) and which collectively have become known as the CHIME framework in the literature. The stages of recovery, identified in only a few of the included studies, were plotted onto the transtheoretical model of change of Prochaska and DiClemente (1982). (Leamy et al., 2011).

The CHIME framework has, since its development, been found to be valid for service users in the UK (Bird et al., 2014), but it was concluded that additional processes might have to be added, such as "practical support", "issues around diagnosis and medication", and "scepticism surrounding recovery" (p. 650), depending on the research context or specific study population. The CHIME framework has also been applied to understand recovery in various settings (for examples see, Brijnath, 2015; Piat et al., 2017; Van Weeghel et al., 2019).

A systematic review on the definition of recovery, conducted by Ellison et al. (2018), drew together the results from 67 articles and found that the dimensions of recovery mentioned most frequently were "individualized/person centered, empowerment, purpose and hope" (p. 97), in relation to the SAMHSA definition of recovery (SAMHSA, n.d.). These most frequently mentioned dimensions are in line with the CHIME framework processes. In a

scoping review of systematic reviews and meta-analyses of 25 articles by Van Weeghel et al. (2019), personal recovery was understood to be a process rather than an outcome, including not only the CHIME processes, but also "responsible risk-taking and coping with challenges" (p. 169).

As a last consideration in the elucidation of what recovery is, I would like to re-iterate the clarification of the reference to individual recovery in the title of this dissertation. This should not be interpreted as an opposing or additional meaning to personal recovery. Recovery was formulated as individual recovery in the title to indicate the fact that the focus of this study is the recovery process of the individual, as opposed to health care system recovery, i.e., the recovery-orientation of health care systems (Davidson, 2016).

In elaborating on the concept and understanding of recovery hereinbefore, what becomes apparent is, as Slade (2009) points out, that recovery cannot be experienced, or is not expressed, in a single way, thus by implication there should not be a single model of recovery-oriented service provision. This is a salient point, especially for this study. In South Africa recovery occurs in environments with specific challenges, such as poverty, inequality and limited resources (Schneider et al., 2016), thus an exploration of the understanding of recovery within South African contexts was necessary in the context of this study, and remains necessary in future.

2.1.2. Barriers to, and facilitators of, recovery

Understanding how recovery occurs in the lives of service users is a further important aspect of elucidating what recovery is. This requires an exploration of the factors that play a positive role in, or detract from, the ability of service users to recognise, engage in and work on their own recovery. These factors can be separated into two categories, namely, barriers to, and facilitators of, recovery. The barriers and facilitators can also be closely related to some of the dimensions of recovery (De Wet & Pretorius, 2020a). As Jacobson and Greenley

(2001) indicate, those internal and external factors which make up recovery are necessary in the promotion of recovery. One of the research objectives of this study was to investigate these barriers and facilitators from the perspectives of service users, carers and service providers in the study setting. It is difficult, if not impossible, to provide an exhaustive exploration of all factors that could influence recovery for service users. What I will discuss here are some of those factors that have been identified as salient in the literature. It is also necessary to bear in mind that for some of the factors related to the one category, i.e., a barrier or a facilitator, the inverse of that factor will be true for the other category, i.e., as a facilitator or a barrier, respectively.

2.1.2.1. Barriers to recovery

Barriers to recovery are those influences in a service user's life which contribute to their not being able to participate, either fully or partially, in their own recovery. These barriers can be in close proximity, such as in the service user's immediate frame of reference, i.e., at home, in their community or services they engage with directly, or further from the service user, i.e., in society or elsewhere (De Wet & Pretorius, 2020a).

In a systematic review of barriers and facilitators of recovery in schizophrenia by Soundy et al. (2015), the barriers were identified as (a) substance use, stigma and relational disconnectedness; (b) lack of confidence by service users in social situations; and (c) the unreliability of the illness trajectory and lack of hope.

In 2018, Wood and Alsawy conducted a systematic review and thematic synthesis of recovery in psychosis from the view of service users and identified barriers to recovery as (a) stigma; (b) being excluded socially, not having an income, unsatisfactory accommodation and no opportunities; (c) substance use; and (d) detrimental experiences in services and side effects of medication.

In the scoping review of systematic reviews and meta-analyses of personal recovery, which also included facilitators and barriers to recovery, Van Weeghel et al. (2019) reiterated and summarised some of the views of Soundy et al. (2015) and Wood and Alsawy (2018) on the barriers to recovery as (a) stigma; (b) detrimental experiences in services; and (c) side effects of medication.

To single out one barrier, stigma seems to be a pervasive and persistent barrier to service users' recovery in the literature (Egbe et al., 2014). Egbe et al. (2014), in a South African study on service users' lived experiences of stigma and discrimination and the effect thereof on their recovery, observed that stigma is imposed by both closer (family and friends) and more distal persons (community members and service providers) in the lives of service users and remains a barrier to their recovery. The authors recommend interventions that target both the home environment and community of the service user which facilitate service users' seeking help and adhering to medication more readily (Egbe et al., 2014). In discussing de-institutionalisation, Parker (2014a) advocates for approaching mental health care not only from a basic needs perspective, but also from a social perspective, in order to address barriers such as stigma. Interestingly, Garverich et al. (2020), in a recent study on the determinants of recovery, found the awareness of stigma not to be a barrier to recovery, possibly linked to the acceptance thereof. This is in contrast to much of the literature (Weeghel et al., 2019) and further validation of this finding in other studies will be beneficial to this field of research.

In South African contexts, the intersection of recovery barriers and general barriers to persons with mental illnesses who make use of public mental health services, such as poverty, inequality, the limited resources in society and violence (Schneider et al., 2016), can make the recovery for such persons even more complex and challenging than in other contexts.

2.1.2.2. Facilitators of recovery

Facilitators of recovery are those influences in a service user's life which contribute to their being able to participate in their own recovery. Once again, facilitators of recovery can be influences in direct relation to the service user or more distal factors in the broader community or society.

In the systematic review conducted by Soundy et al. (2015), the facilitators of recovery in schizophrenia were identified as (a) acceptance and re-defining the illness; (b) recognising the role of medication, responsibility and staying busy; and (c) receiving support from family, friends or peers and faith as a way of belonging.

In Wood and Alsawy's (2018) systematic review of qualitative studies, the facilitators of recovery from psychosis were found to be having (a) support, with family being most important; (b) religious belief; (c) hope and self-directedness; (d) resources, to address basic needs as well as services; and (e) mental health services that are centred around the service user.

Van Weeghel et al. (2019) again re-iterated and summarised the views of Soundy et al. (2015) and Wood and Alsawy (2018), this time regarding the facilitators of recovery. The facilitators were (a) faith; (b) service user self-directedness; and (c) support of the service user (Van Weeghel et al., 2019). More recently, the support of service users was repeated as an important facilitator of recovery (Garverich, 2020).

It seems, from the international literature, that hope has also been repeatedly identified as an important facilitator of recovery (Andresen et al., 2003; Chandler et al., 2013; Davidson et al., 2005; Jacobson & Greenley, 2001). A recent study from Ethiopia concurred with this, by finding hope to be a strong predictor of recovery (Temesgen et al., 2019). As such, hope is even included as one of the recovery processes in the systematic review and narrative synthesis resulting in the CHIME framework (Leamy et al., 2011). Hope in

recovery, like stigma, can be pervasive and persistent. Hope, however, has also been experienced as having the potential to counter stigma (Ponte, 2019).

In a South African study on how service users and their carers perceived psychosocial disability in schizophrenia, facilitators such as constructive service user relationships with family and service providers, service users having work or activities to keep occupied, traditional healers and faith were identified (Brooke-Sumner et al., 2014). Many of these facilitators are similar to those found in the international literature (Van Weeghel et al., 2019), although they might have different practical applications in local settings.

It is generally accepted that how mental health services are delivered can play an important facilitative (or potentially negative) role in the individual recovery of service users. It is for this reason that the recovery-orientation of services or interventions is studied and promoted in so many settings (Le Boutillier et al., 2015). In a systematic review, investigating how recovery-oriented interventions can contribute to personal recovery, the ways in which such interventions can facilitate recovery were revealed to be the (a) provision of skills; (b) furtherance of a therapeutic alliance between service provider and user; (c) setting of an example of recovery by peer support workers to service users; and (d) enhancement of the chances and options for service users (Winsper et al., 2020).

Services and interventions in the public mental health sector in South Africa are not yet formally delivered from a recovery-oriented perspective. Encouragingly, though, the government has recently included reference to the recovery model and, in addition, included the Ekurhuleni Declaration on Mental Health of April 2012, which refers to a commitment to "fostering [sic] person-centred recovery paradigm that respects the autonomy and dignity of all persons" as a basis for the delivery of their services, in its NMHPF (South African Department of Health, 2013) (see section 2.1.6. for more details on this). This is an encouraging step and I hope that the recovery paradigm referred to in the NMHPF will be

formally implemented and recognised in South African public mental health services soon by paying specific attention to the way in which such services should be implemented practically, in empowering, meaning-making and hopeful ways (Lloyd et al., 2008), to support recovery optimally. If done in this way, the services could have the potential of facilitating the recovery of service users (Lloyd et al., 2008).

2.1.3. Overview of the history of modern conceptualisations of recovery

The concept of recovery was first used in relation to physical disabilities before it became common in the field of psychiatric disabilities (Anthony, 1993; Parker, 2012; Spaniol, 1991), where recovery was initially primarily explored as a concept in relation to the most severe of mental illnesses, namely schizophrenia. However, it was soon progressively explored in other specific disorders (for example, see Tse et al., 2013 and Veseth et al., 2012 for recovery in bipolar mood disorder; Ng et al., 2016 for recovery in borderline personality disorder) as well as various psychiatric disabilities (Young & Ensing, 1999). This widening of the applicability of the concept of recovery to a range of psychiatric disabilities may be because of the realisation and acknowledgement, within the larger psychiatric and even general community, of recovery scholars' long-time assertion that the commonality in the nature of human experiences places each and every human's functioning somewhere on a spectrum of mental health. This is a positive change that might indicate the slow dissolution of the imaginary barrier between "them and us" (Richards, 2010, p. 40).

The concept of mental health recovery has been in use since the Kraepelinian era (Ramon et al., 2007), but then rather to denote clinical recovery. A move to modern conceptualisations of recovery (see sections 2.1.1.3 to 2.1.1.10) can largely be traced back to the 1980s and 1990s. This recovery movement followed on the consumer movement of the 1960s, which advocated for the rights of consumers and a consumer-oriented approach to marketing and trade. The consumer-oriented principles and policy changes that were brought

about during the consumer movement increasingly placed services and policies in various sectors, the mental health sector included, under the microscope and ultimately gave rise to patient-oriented services and policies within the mental health sector (Ramon et al., 2007).

The changes in orientation to more service user-centredness, regard for service user experience, deinstitutionalisation (Spaniol, 1991), the social model of disability, some positive long-term outcomes in major schizophrenia studies (De Girolamo, 1996; Harding et al., 1987; Sartorius et al., 1974) and increasingly published service user accounts (Deegan, 1988; Leete, 1989) provided a platform for the consideration of recovery as a viable trajectory for mental health service users (Ramon et al., 2007). One of the seminal articles referring to the concept of recovery as it is used today, is that of the American clinical psychologist, Patricia Deegan in 1988, who was diagnosed with schizophrenia in her youth.

Modern conceptualisations of recovery in the literature have developed in many countries across the world, with scholars in countries such as the USA, the UK, Australia and New Zealand being the main proponents. Other approaches to psychiatric illness, which could be aligned with recovery, have emanated from European countries in the work of Romme and Escher in the Netherlands, the Italian Psychiatric Reform (Ramon et al., 2007) and Trialogues in Germany (Slade et al., 2008). Approaches in Norway, such as Open Dialogue, and the work in Italy, for instance, have a strong focus on aspects of experiences in mental illness, which could be regarded as similar to aspects of recovery as explored in the wider international literature (Borg & Kristiansen, 2004). Acknowledgement is given to the contributions of these approaches in other countries to the understanding and advancement of recovery, however, it falls outside the scope of this section to incorporate the history of these approaches. The focus in this section is on a brief overview of how recovery developed internationally.

The concept of recovery was first included formally, as part of policy in the field of psychiatry in the USA in their Report on Mental Health in 1999 (United States Department of Health and Human Services, 1999). The report stated that, "All services for those with a mental disorder should be consumer oriented and focused on promoting recovery" (Davidson et al., 2010; United States Department of Health and Human Services, 1999, p. 455). The report further stated that the mental health services should not only be aimed at symptom alleviation, but also at the "restoration of a meaningful and productive life" (United States Department of Health and Human Services, 1999, p. 455). Other developed countries' governments, such as those of Australia, UK, Canada and New Zealand, followed suit in time (Australian Department of Health, 2009; Canadian Mental Health Commission, 2012; New Zealand Mental Health Commission, 2012; United Kingdom Department of Health, 2011). The strategy and policy changes that ensued were aimed at providing for the acknowledgement and inclusion of recovery as a value and principle and the adaptation of the mental health services of these developed world governments to move towards a recovery-orientation. As a result, in these developed countries, programmes to promote individual mental health recovery have proliferated and services have been scaled up to provide for their recovery-orientation.

O'Hagan (2001), upon discussing the international roots of recovery in a manual aimed at New Zealand mental health workers, advises that in more collectivist cultures outside of the USA, where the recovery movement has its origins to a large extent, recovery literature should focus more in-depth on aspects such as stigma, community involvement, inclusiveness and human rights (p. 2). As O'Hagan (2001) goes on to point out, in New Zealand persons of Maori culture might feel more comfortable in referring to the autonomy of the group, rather than the individual, which is the focus in more individualistic cultures.

This is also a relevant suggestion in South African contexts that consist of various cultures, many of whom have a collectivist nature or roots.

The increase in peer-reviewed recovery literature over the past approximately 30 years also gives an indication as to the rise in prominence of the recovery field as a recognised academic field of study over time. Schizophrenia Bulletin, which was established in 1969, is a prominent journal with a current impact factor of 7.289 (Schizophrenia Bulletin, 2020), in which peer-reviewed articles about mental health recovery are often published. The first such article that was found in which the term recovery was used was in 1989 (Leete, 1989). It is significant, if the understanding of mental health recovery as a unique and individualised process is borne in mind, that the article was a first-person account by a service user and not an academic article by a recovery scholar. Since then, Schizophrenia Bulletin, known for publishing clinical research, has become known to also publish regular first-person accounts by service users about their experiences of mental illness. This has contributed to the growing awareness in the psychiatric or clinical community of the importance of service user-centred attitudes and services that are developed in collaboration with service users themselves. As Byrne et al. (2018) has urged, the global mental health community should integrate the expertise of persons with lived experience in senior positions within mental health structures.

Another peer-reviewed journal that often publishes articles on mental health recovery is The Psychiatric Rehabilitation Journal, which was established in 1976 as The Psychosocial Rehabilitation Journal. The early editions of The Psychiatric Rehabilitation Journal published articles on the topic of rehabilitation, which term was often used to describe what would later be regarded as recovery (Holland & Holland, 1980). The first article that addressed the topic of recovery per se was, *Recovery: The lived experience of rehabilitation*, by Patricia E. Deegan (1988), a service user and recovery scholar.

World Psychiatry, which was established in 2002, is yet another, more recent journal with often publishes recovery articles. An article by Dinesh Bhugra in 2008, on the topic of the training of psychiatrists in the UK, was the first article found to refer to mental health recovery in this journal. One of the older journals in the field, The International Journal of Social Psychiatry, was established in 1954 and publishes research in the field of recovery, as part of their scope to promote the publication of research on the influence of social factors on mental health. Even in the very first issue in 1955, an article by Dr G. M. Bell of the then Dingleton Hospital in the Scottish Border Region was published that reads like a latter-day article on modern recovery principles applied in a psychiatric hospital setting with in-hospital service users (Bell, 1955).

To conclude this section, recovery, having its roots in the physical disabilities literature, has been referenced in the psychiatric literature since the Kraepelinian era. It is, however, only in the past 30 years that it has been used in the personal recovery sense. The recovery scholarly literature is now published across several prominent international journals, indicating its rise in prominence. Formal acknowledgement and inclusion of recovery in policies started in the USA and extended from there and is now also included in the South African NMHPF (South African Department of Health, 2013). This brief overview of the history of modern conceptualisations of recovery provides a basis to further explore the South African context and mental health recovery in South Africa, as the focus of this study.

2.1.4. South African context

In order to create a backdrop for the study, a broad description of the overall context of South Africa as well as the Western Cape, where the study took place, is provided in this section. South Africa falls in the category of upper middle-income countries, according to data from the World Bank Group (World Bank Group, 2020), with a population of 55.7 million people at last official count in 2011 (Statistics South Africa, 2011). Despite South

Africa's status as an upper middle-income country, many challenges exist and remain in its society. South Africa struggles with issues of high poverty rates and sparse resources and with having one of the most unequal societies in the world (World Bank Group, 2018). These challenges, poverty, sparse resources and inequality, spill over from the general society into public health services (Benatar, 2013; Omotoso & Koch, 2018) and, as a result, into public mental health services. These challenges, together with the underdevelopment, underfunding and largely institution-based delivery of public mental health services, pose specific challenges to the South African public mental health system (Docrat et al., 2019; N. Jacob, 2015; Kleintjes et al., 2013; Lund et al., 2012; Parker, 2012; Stein, 2014; Sunkel, 2014). The connection between mental illness and poverty has been cited as contributing to the lack of attention to the recovery of public mental health care service users in South Africa (Kleintjes et al., 2013).

Within South Africa, the population of the Western Cape Province, where the study was conducted, stood at 5.8 million in 2011, with the language most spoken being Afrikaans, followed by Xhosa and English. Afrikaans and Xhosa are local South African languages. In the Western Cape, 80.6% of the population have some secondary schooling or higher (Statistics South Africa, 2011). The unemployment rate in the Western Cape in 2011 was 21.6% (Statistics South Africa, 2011). In 2019, 65,7% of households in the province were of vulnerable class or lower (Statistics South Africa, 2019). As a result, the majority of South Africans (84%) are reliant on public mental health services (Docrat et al., 2019).

In the Western Cape, similar to the rest of South Africa, many barriers to public mental health care access exist with the government not placing priority on mental health (De Wet et al., 2019; Docrat et al., 2019). Approximately 5% of the total national health budget is spent on mental health, with that percentage increasing to 7.7% in the Western Cape, being the highest in the country. Of the mental health budget, most is spent on in- and out-patient

services. The majority (90.5%) of the expenditure for these two services is spent on in-patients in the Western Cape (Docrat et al., 2019).

The emphasis in public mental health settings is on symptom relief (Kleintjes et al., 2012), possibly due to limited resources and great pressure on service providers to discharge service users as soon as possible. Service providers are often compelled to, although they do not want to, discharge service users prematurely, to make provision for other service users who are more acutely ill and require their services, which results in the revolving door phenomenon of repeated re-admissions (Docrat et al., 2019) to the detriment of the mental health of those service users. Such a confluence of circumstances also means that often the service providers are willing to, but cannot support service users in their recovery journey. According to Kleintjes et al. (2012), what is needed is a move towards empowerment of service users socially and economically, so that service users can benefit at all levels of interaction. In addition to increased funding to enable the development of public mental health services through increased resources, which would provide opportunities for service providers to become recovery-oriented, service users and other non-service providers should be equipped to be involved in recovery work on various levels, including policy reform (Kleintjes et al., 2012).

Regarding the worldwide trend towards shifting mental health care from institution-based care to community care, Sunkel (2014) warns that in South African contexts such deinstitutionalisation should not be seen by the government as a means to cut the budget for mental health services. She warns that funding that would have been channelled to institutions should be re-routed towards community initiatives that support service users outside of institutions (Sunkel, 2014). Brooke-Sumner et al. (2016) report that such re-allocation of funds from institutional spending to community spending does not necessarily take place in South Africa, perhaps because of the complex nature of the undertaking. The

channelling of funds from institutions to communities was re-iterated by the South African Human Rights Commission in their Report of the National Investigative Hearing into the Status of Mental Health Care in South Africa (South African Human Rights Commission, 2019). Given this state of affairs in South Africa, many public mental health service users are still reliant on institutional-based care for their mental health, which care is mostly focused on symptom relief.

2.1.5. Public mental health care service users in the South African context

The description of the overall context of South Africa and the Western Cape, more specifically, provides the backdrop for the study. While data on the understanding of recovery in this study were collected from three groups of persons, including service users, service providers and carers, the persons central to this study were service users. The inclusion of service providers and carers in the collection of the data served the exploratory aspect of the study and elucidated perspectives on recovery from various sources, assisting in obtaining a rich and broad understanding of recovery in the study context. Service users are persons who make use of mental health services or who live their lives with a mental illness.

Slade (2009) emphasises the fact that personal experience is the focal point in recovery. This places the service user at the centre of recovery work and accounts for the large amount of qualitative work that is done in the recovery field (Leamy et al., 2011). Recovery scholars want to, first and foremost, understand recovery from the perspective of the individual service user (Slade, 2009). For this reason, it is important to describe who the service users were in this study, apart from the criteria-driven description of the participants in section 3.2. in Chapter 3.

To clarify, service users is one term that is used to denote persons, who make use of mental health services or live with a mental illness in the literature. Other terms, such as consumers, clients or patients are used interchangeably in the literature to refer to persons

who make use of mental health services, often depending on the context or perspective of the authors (Fischer et al., 2020). Some terms are associated with individuals who bring influence to bear in achieving what they set out to achieve, such as consumers or service users, while other terms, such as patients, are associated with diminished influence (Fischer et al., 2020). I prefer to use the terms service user, which is predominantly used in the literature, throughout this dissertation.

The service users in this study, i.e., the participants in the qualitative data collection activities, were persons who were reliant on public mental health services. This means that these persons were not able to access the more resource-rich and comprehensive private mental health care which serves the affluent (approximately 16%) in the South African population (Docrat et al., 2019). This implies a vulnerability of these public mental health service users in terms of financial and community resources, as I discussed in the previous section, and limitations on access to sufficient mental health care. Some of these service users may possibly have been subject to stigma and discrimination within their communities and even when seeking treatment (Egbe et al., 2014), which surely made it more challenging for them to seek and/or obtain the help that they may have wanted. In the communities in the Western Cape, where these service users hail from, substance use, with methamphetamine use being most common, is rife (South African Community Epidemiology Network on Drug Use, 2019), which also increases the vulnerability of these service users to dual diagnoses of mental illness and substance use. Because of their contextual vulnerabilities and limitations, some of these service users were perhaps less able to exercise agency and have choices within their communities, but also in their treatment, than more affluent service users. Overall, this translates to the psychosocial disability of these service users. Psychosocial disability refers to the inability of persons, who are faced by mental health challenges, to engage in society because of the intersection between their mental health challenges and

other social obstacles (Kleintjes et al., 2013). Psychosocial disability is enduring and such persons face many problems in attempting to give voice to their own mental health needs and care in South Africa (Kleintjes et al., 2013) and consequently struggle to be empowered to take up responsibility for, or play a meaningful role in, their own recovery. This is borne out in the two sections that follow, which emphasise that a paucity of recovery focus and recovery programmes in South Africa still exists.

2.1.6. Recovery in South Africa

Recovery in South Africa is still in its infancy. There are pockets of research being conducted and literature being published in this regard (for example, see Bila, 2019; Brooke-Sumner et al., 2014; De Wet & Pretorius, 2020b; De Wet et al., 2015; De Wet et al., 2019; Gamieldien et al., 2020; Kleintjes et al., 2013; Parker, 2012), but much exploration and understanding is still necessary to develop a field of knowledge on recovery in South Africa. This is one of the main reasons for this study.

At a political level in South Africa, the term recovery has recently been included in the South African NMHPF (South African Department of Health, 2013). The NMHPF refers to the recovery model and defines it as,

> An approach to mental health care and rehabilitation which holds that hope and restoration of a meaningful life are possible, despite serious mental illness. Instead of focusing primarily on symptom relief, as the medical model dictates, recovery casts a much wider spotlight on restoration of self-esteem and identity and on attaining meaningful roles in society. (p. 8)

This definition of the recovery model is in line with the understanding of personal recovery in the literature (Anthony, 1993; Deegan, 1988) and its inclusion in the NMHPF holds hope for the integration of recovery into public mental health services in the future.

One of the objectives in the NMHPF is the provision of support to service users and their carers in their communities to advance mental health and recovery. In addition, one of the NMHPF's values is recovery and is amplified by the principle that services should be delivered in such a way as to support service users in returning to, or taking up, positions in their community, which they elect. Another value of the NMHPF is community care, which should be supported by one of its principles, a recovery model. The objective, together with these values and their principles, provides an imperative for public mental health services in South Africa to be recovery-oriented and for recovery-oriented programmes to be established. Despite this imperative, however, very little, if any, formal recovery-orientation has been implemented in services (Bila, 2019) and few recovery-oriented programmes have been established in the public mental health care sector (De Wet et al., 2019; The Spring Foundation, n.d.). The reason might be that recovery in developed settings is supported by well-equipped resources and budgets that allow service users opportunities to explore their options in terms of recovery (Brooke-Sumner, 2016). In a low- or middle-income country like South Africa, fewer resources and even less, if any, budget allocations that are aimed at the pursuit of recovery are available. Bila (2019), in a study amongst South African social workers from non-governmental organisations, found that their knowledge of recovery was minimal and recovery-oriented practice lacking. This might be linked to the insufficient resources to train service providers in recovery and recovery-oriented practice in South Africa. Thus, although the ideals of recovery have been included in policy documents, such as the NMHPF (South African Department of Health, 2013), the scarcity of resources might mean that few of these recovery ideals can be employed in services to benefit service users. More recently, the failure to implement the NMHPF (South African Department of Health, 2013) fully has been reported by the South African Human Rights Commission (2019).

Byrne et al. (2018), in discussing the importance of appointing persons with lived experience in senior positions in the mental health sector, indicate that employing peer support workers in mental health settings in developing countries with limited financial resources (South Africa is an example of such a country) could be a viable solution to promoting recovery in such countries. Their suggestion is to initially include leaders with lived experience who would in turn be able to prepare peer support specialists for such roles.

In considering how the advancement of recovery in South African contexts should be approached, applying generally accepted individualistic conceptualisations of recovery from developed settings directly into South African settings must be recognised for its shortcoming, this inherent in the fact that emphasis might be placed on the responsibility of the individual, whereas in South African settings the focus might rather be on the collective, the community, in taking responsibility for recovery (Leamy et al., 2011; Onken et al., 2007; Price-Robertson et al., 2017). Tse and Ng (2014) warn, however, that mental health services need to encourage service users and their families to participate in the recovery process by taking into account the cultural complexities in communities and not merely distinguishing in a dichotomous way between individualistic and collectivist cultures. Stevens (2018), in discussing Frantz Fanon's contribution to non-traditional ways of understanding mental illness, underscores the importance of Fanon's view, especially in environments within South Africa, that mental health (and by extension then, recovery) should not only be considered from a psychological perspective, but contextual influences should also be taken into account. Jacobson and Farah (2012) furthered Jacobson and Greenley's (2001) development of dimensions of recovery, which consisted of internal and external factors, by developing an improved model of recovery which they suggest is more culturally sensitive than that of Jacobson and Greenley (2001). Jacobson and Farah's (2012) model took cognisance of the distinct nested relationships of service users within the environments in which they may be

located, when considering recovery. For them, amongst other things, the social determinants of health must be made more visible when thinking about recovery (Jacobson & Farah, 2012). This model exemplifies that, in future advancements in recovery research in South African contexts, recovery must be understood from various cultural perspectives and from the context within which service users experience their recovery, such as the Western Cape province of South Africa in this study, as opposed to an understanding based on individual experience.

2.1.7. Recovery-oriented programmes in South Africa

As mentioned, few recovery-oriented programmes exist in South Africa. In searching for formal literature or general internet information in recovery-oriented programmes in South Africa, it became apparent to me that it is necessary to explore the distinction between mental health and addiction recovery. Although mental health and addiction recovery domains are often grouped together under, and addressed by, the same organisations (e.g., SAMHSA in the USA, see https://www.samhsa.gov/), and good reasons exist for this (for a detailed discussion, see Davidson and White, 2007), the differing definitions in mental health recovery and addiction recovery may pose challenges for service providers in translating these into practice (Brekke et al., 2018; Corrigan et al., 2019).

In South Africa, private mental health care programmes have been established, some being referred to as both addiction and mental health recovery (for example, see http://twinriversrehab.co.za/) programmes, although it is not clear from the information available on their websites whether these programmes are truly recovery-oriented or simply treatment centres for mental health and substance use disorders. Other South African private health care programmes purporting to be aimed at mental health recovery also exist (for example, see https://www.papillon.org.za/; http://palmtreeclinic.com/). Once again, it is not clear from the information about these programmes whether they are based on true recovery-

orientation in line with personal recovery understandings in the literature (Anthony, 1993; Deegan, 1988) and the conceptual underpinnings of this study and of certain treatment centres.

In the public mental health sector in South Africa, few dedicated mental health recovery programmes exist. Psychosocial programmes, aimed at the development of vocational and social skills, exist, but are often merely residential care facilities (C. Sunkel, personal communication, March 7, 2018), or day centre services which are offered via public psychiatric hospitals or primary care clinics. These psychosocial programmes fulfil an important role in supporting service users, but the programmes are not based on the understandings of personal recovery expounded in the literature (Anthony, 1993; Deegan, 1988), neither are the services necessarily provided from a place of formal recovery-orientation by staff. Only a few mental health recovery programmes have existed in recent years in South Africa (C. Sunkel, personal communication, March 7, 2018; De Wet et al., 2019; The Spring Foundation, n.d.), albeit on a much smaller scale than internationally, to support individual service users' recovery and to promote the recovery-orientation of services.

One of the few programmes that is based on Jacobson and Greenley's (2001) conceptualisation of recovery (refer to section 2.1.1.10 for more detail), and thus constitutes a truly recovery-oriented programme, is The Spring Foundation (The Spring Foundation, n.d.) in the Western Cape Province of South Africa (see their website, www.thespringfoundation.org). The Spring Foundation aims at promoting recovery by "finding hope for recovery through re-connection" through their programmes (The Spring Foundation, n.d.). The Spring Foundation is based on the grounds of one of the tertiary psychiatric hospitals in the Western Cape, being one of the study sites, and was established in 2011 (De Wet et al., 2019). Under the umbrella of The Spring Foundation, several recovery-

oriented programmes have been established, such as a market garden (cultivation of vegetables for sale), youth project (music and dance programmes), wheelchair clinic (maintenance of wheelchairs by longer term service users) and identity document project (donations from public to support service users with the fee to re-obtain their identity documents for purposes of obtaining a disability grant upon discharge. On the importance of, and struggles to obtain identity documents in South Africa in general, see Boshoff, 2016). These programmes are all based on the recovery dimension of hope, which is facilitated at The Spring Foundation through re-connection (De Wet et al., 2019; The Spring Foundation, n.d.). All the programmes at The Spring Foundation are based on some form of re-connection for service users (The Spring Foundation, n.d.). The need expressed by a service provider at The Spring Foundation to measure the recovery of service users and thus gauge the possible impact of their programmes, provided impetus to undertake this study.

2.1.8. Existing instruments to measure recovery

The literature confirms that many recovery measures have been developed internationally (Shanks et al., 2013; Sklar et al., 2013) and these measures are aimed either at measuring recovery in the individual, from different perspectives, i.e., service users, carers or service providers (Drapalski et al., 2012; Giffort et al., as cited in Corrigan et al., 2004; Luscszakoski et al., 2014; Neil et al., 2009; Onifade, 2011; Williams, Leamy, Bird, et al., 2015), or, on the other hand, at measuring the recovery-orientation of the health care providers, services and institutions (Dumont et al., as cited in Sklar et al., 2013; O'Connell et al., 2005). In this study, my focus is limited to measures of individual recovery of service users. Since no measure for individual recovery has been found to be developed for a South African context, nor an overall optimum measure of individual recovery in the international domain that could be adapted for a South African context (Shanks et al., 2013), the development of such a measure was the primary motivation for the study. The development

of the measure makes it possible for service users, together with persons involved in their care, such as carers and service providers, to use the results from the administration of the measure as a point of departure for discussions about the recovery process for the service user.

In developing an individual recovery measure, it was firstly necessary for me to identify the existing individual recovery measures in the literature and identify those that have been found to be evidence-based and most robust and to determine the context and service users for which they were developed. This was to determine where the contribution of this study would be located.

The first research projects that were found to be commissioned to consolidate the literature on individual recovery measures, were two compendia commissioned by The Evaluation Center at the Human Sciences Research Institute in the USA. The first compendium was by Ralph et al. (2000) and the second, by Campbell-Orde et al., followed in 2005. The first compendium included eight early measures of individual recovery and 10 measures related to recovery. The second compendium not only included nine measures of individual recovery, such as the Illness Management and Recovery Scales (IMR), the Recovery Assessment Scale (RAS) and the Mental Health Recovery Measure (MHRM) that have also been included in more recent reviews (Burgess et al., 2011; Cavelti et al., 2012; Law et al., 2012; Scheyett et al., 2013; Shanks et al., 2013; Sklar et al., 2013), but also included four, as it was termed, “measures of recovery promoting environments” (p. 7) or, what would be referred to today as, measuring the recovery orientation of systems (Campbell-Orde et al., 2005; Ralph et al., 2000). These two compendia formed the basis of an Australian review of recovery measures (both personal and of the recovery orientation of systems) by the Australian Mental Health Outcomes and Classification Network in 2010 that was published in an article by Burgess et al. in 2011. As part of the review, Burgess et al.

(2011) assessed 22 individual recovery measures and of those found the RAS, IMR, Stages of Recovery Instrument (STORI) and the Recovery Process Inventory (RPI) to be the most suitable for the Australian context.

Shortly after Burgess et al. (2011), Law et al. (2012) conducted a review in the UK. The review team included service users in order to rate the acceptability of the measures from a service user perspective, in the spirit of personal recovery. Law et al. (2012) examined six self-report measures of individual recovery, namely the IMR, Psychosis Recovery Inventory (PRI), Questionnaire about the Process of Recovery (QPR), RAS, RPI as well as the STORI and concluded that the RAS was the measure with best validity and acceptability at the time of the study.

In a Swiss study by Cavelti et al. (2012), the literature on measures of individual recovery from schizophrenia or severe mental illness were reviewed, albeit not through a systematic review. Cavelti et al. (2012) identified 13 measures of individual recovery and concluded that the RAS was the best measure, at the time. The authors warned, however, that because individual recovery is subjective in nature, it makes the measurement thereof complex and that the information available at the time of their study was not sufficient to draw a final conclusion, resulting in the need for more research (Cavelti et al., 2012). Sklar et al. (2013), however, in their systematic review published a year later, remarked that Cavelti et al. (2012) did not describe the service user involvement in the development of measures included in their review. This was regarded as a void in the review, since the spirit and philosophy of recovery is based on the involvement of service users (Sklar et al., 2013).

In the USA, Scheyett and colleagues (2013) conducted a literature review of individual recovery measures and, like Law et al. (2012) and Sklar et al. (2013), placed particular emphasis on whether consumers were involved in the development of the measures. Scheyett et al. (2013) examined 12 measures of personal recovery and concluded

that it would be necessary for service providers to determine how a service user would define recovery for herself or himself and then select a measure most fitting based on that definition. Scheyett et al. (2013) found consumer involvement to be highest in the MHRM, RAS, STORI, Self-Identified Stages of Recovery and the Short Interview to Assess Stages of Recovery. Reliability and validity was highest in the Consumer Recovery Outcomes System, RAS and RPI. Scheyett et al. (2013) also remarked that most measures were not examined as to whether they indicated change over a period of time, and that only discussions about the MHRM and the CROS included a reference to such responsiveness.

Aside from the above reviews, two comprehensive and systematic reviews on individual recovery measures were done in 2013, one by a team of researchers from the USA and the other by a team from the UK.

The USA systematic review conducted by Sklar et al. (2013) was published first and identified 13 measures of individual recovery and reviewed them according to their psychometric properties, the level of involvement of service users in the measure's development and how much effort was required to administer the measure. In the light of these criteria, the RAS, which measures recovery from the service user's perspective, was found to be the most highly recommended by the authors. The RAS is based on certain concepts related to recovery, such as empowerment, confidence, hope and the participation of friends and family in the service user's process of recovery. The RAS was highly recommended by the authors, because of its wide use, having the soundest psychometric properties of all the measures included and its ease of administration, although the rating of service user involvement was not as high as that of the Maryland Assessment of Recovery in People with Serious Mental Illness (MARS), which also measures individual recovery from the service user's perspective. The MARS is based on the widely accepted definition of recovery by the USA Substance Abuse and Mental Health Service Administration

(SAMHSA), which consists of four dimensions and 10 “guiding principles” (SAMHSA, n.d., pp. 3–4). The MARS was ranked second in the Sklar et al. (2013) review because of its adequate psychometric properties and high service user involvement rating, although it was not as easily administered as some of the other measures.

The other systematic review was conducted in the UK by Shanks et al. (2013). It was published shortly after Sklar et al.’s (2013) review, in October 2013. Shanks et al. (2013) identified 13 individual recovery measures from the literature. Firstly, Shanks et al. (2013) set out to determine how well these measures fit with their CHIME framework, which is the conceptual framework they generated in 2011 to characterise the recovery journey, identify the recovery processes and describe the recovery stages using the transtheoretical model of change (Leamy et al., 2011) (refer to section 2.1.1.10. for more detail). This framework assists in identifying inclusion requirements when measuring recovery. Furthermore, Shanks et al. (2013) examined how the identified measures held up psychometrically. Of those identified measures of individual recovery, eight overlapped with the review by Sklar et al. (2013), most notably the RAS and the MARS. Shanks et al. (2013) included the QPR, which Sklar et al. (2013) strikingly did not, and found it to be the most closely linked to the CHIME framework. The QPR measures recovery from the service user’s perspective. In addition, Shanks et al. (2013) found the RAS to be the most widely published of those measures in their review. Of the included measures, the RAS and QPR were also found to have the strongest evidence base. Although no measure had a full psychometric evaluation at the time, the MARS, RAS and QPR were rated amongst the top measures in terms of the extent of psychometric properties (Shanks et al., 2013). At the time of the review, a Chinese version of the QPR had already been found reliable in a Hong Kong sample (Chien & Chan, 2013). Since the systematic review by Shanks et al. (2013), the QPR has been found to have good psychometric properties in one UK sample (Law et al., 2014), where it was re-evaluated by

its developers (Neil et al., 2009), and satisfactory psychometric properties in another UK sample (Williams, Leamy, Pesola, et al., 2015) as well as showing optimistic psychometric properties in a version for the Swedish context (Argentzell et al., 2017). The QPR is a favoured measure in the UK mental health system (Law et al., 2014). The RAS has also been tested in various settings, such as Australia (McNaught et al., 2007), Japan (Chiba et al., 2010) and Portugal (Jorge-Monteiro & Ornelas, 2016) and found to have validity and reliability in these settings.

From the examination of the literature, especially the systematic reviews by Sklar et al., (2013) and Shanks et al., (2013), on individual recovery measures, I drew the conclusion that the existing international individual recovery measures that demonstrated a widely acceptable underlying definition of recovery, good or adequate psychometric properties, ease of administration, as well as wide publication in the literature, are the RAS, the MARS and the QPR. I used these internationally recognised and well-reviewed recovery measures to inform the development of the individual recovery measure in this study for service users in a South African context. For more details about the use of these existing measures in the development of the measure in this study, see Chapter 3, section 3.7.

2.1.9. Measurement of mental health recovery in South Africa

In a search of the literature pertaining to South Africa, no local measures to determine the individual recovery of service users have been found to have been developed as of yet. Nor does the literature reveal a generally-accepted international measure of individual recovery that should be adapted for a South African context (Shanks et al., 2013).

In being informed by the international literature while developing the recovery measure for a South African setting, it was important to take note of the warnings offered by Foxcroft (2004) regarding the planning of the development of psychological measures in general for South Africa. Foxcroft (2004) warns that cultural aspects need to be borne in

mind at the planning stage of the measure, rather than paying attention to cultural aspects once items are being formulated. It was thus important for me to stay cognisant of the limitations in usefulness of the international measures which I had identified to assist me in the development process from the start of the study. In planning a psychological measure to be developed for a South African context, Foxcroft (2004) highlights, amongst others, (a) that the diversity of the context has to be contended with; (b) the level of schooling and understanding of the underlying construct by the target population; (c) that a contextually relevant theory should be developed to form the basis for the new measure; and (d) that the format and presentation of the measure be suitable to the target population and their worldview (Foxcroft, 2004). In this study attention was paid from the outset to these important caveats by Foxcroft (2004) and integrated in the discussion of the development of the measure in Chapter 3.

Furthermore, in consideration of the findings that no recovery measure for a South African setting nor a generally-accepted international recovery measure, that should be adapted existed as well as the recommendations by Foxcroft (2004), the development of a new individual recovery measure, as opposed to employing one of the existing international measures identified, was regarded as necessary because of the unique challenges that are faced, such as poverty, inequality and limited resources (Schneider et al., 2016), and which translate to distinct and nuanced meanings that could be attributed to the recovery concept by service users in South African settings.

As a last consideration for the development of a recovery measure for a South African context, I reminded myself that South Africa has a history of segregation and, consequently, a disproportionately small amount of, and often severely inadequate, largely under-resourced and mostly institutionally-based public mental health resources are allocated to the majority of persons in its society, who rely on these resources (J. Parker, personal communication,

June 19, 2017). Within this context, as described in more detail in section 2.1.4., I expected public mental health service users and the carer and service provider participants in this study to have very different notions of recovery-related concepts to those of service users in developed world settings where existing recovery measures have their origin. I expected the recovery notions of the study's participants, who are faced with contextual challenges, to be informed by the insecurities that they face and the (in-)ability of relevant government departments to sufficiently address, at times, the needs that arise from these insecurities. Service users within South African contexts do not have access to the same rich resources and support that service users in developed settings have (Brooke-Sumner, 2016). Thus, even though I expected that some of the dimensions of recovery identified in the international research might be found to correlate with local conceptualisations of recovery, some of these dimensions were found, for some service users, to have different content or practical application and informed me in the development of the measure.

2.2. Theoretical framework

A theoretical framework is a crucial consideration in the research endeavour (Bryman, 2016b). A theoretical framework gives a starting point for the research process, an understanding of the researcher's position in relation to the research, that is the researcher's worldview or paradigm, and indicates what lenses may be used to analyse or interpret and understand the data collected during the research process (Bryman, 2016b). The various aspects of the theoretical framework will be discussed in this section of the chapter.

2.2.1. My ontological and epistemological position

The ontological and epistemological position of the researcher gives the study audience an understanding of how the researcher views the reality that is the subject of the study and, therefore, the researcher's approach to the research endeavour. The differences in opinion surrounding the definition of mental health recovery, as described in the literature

review, also necessitates making my own position as researcher in this study ontologically and epistemologically clear and emphasises the alignment of this position with the particular understanding of recovery that is the guide for this study.

Ontology describes what reality is in the realm of studying it and how it is regarded as a reality by the researcher (Guba & Lincoln, 1994; Silverman, 2017; Terre Blanche & Durrheim, 2006). In this study, I take up a relativist ontological position, since I regard the social reality of mental health recovery as consisting of subjective experiences and not objective facts. The social reality is linked to how people position themselves in relation to it. I regard the social reality as having the possibility of being fluid and changing and that it is dependent on people and the roles they play in such reality. I do not regard a social reality as existing independently of people. The social reality is a product of the actions of people engaging within social situations (Terre Blanche & Durrheim, 2006).

Epistemology is closely linked to, and determined by, the researcher's ontological position and is concerned with how the researcher thinks about the production of knowledge (Guba & Lincoln, 1994; Silverman, 2017; Slade, 2009; Terre Blanche & Durrheim, 2006). My epistemological position is an interpretivist one, according to Terre Blanche and Durrheim (2006) (or naturalist, according to Silverman, 2017; subjectivist, according to Guba and Lincoln, 1994). Such an interpretivist stance means that my "model of reality" (Silverman, 2017, p. 134) is to regard the production of knowledge as a pragmatic activity. I regard the generation of the results as the manner in which the knowledge is created and I do not believe the knowledge exists as objective facts that must be found. I believe that I, as researcher, have an influence on the data collection and analysis process and that I do not stand separate from the research process observing, but rather interacting (Guba & Lincoln, 1994).

The foundation on which the research is based is my own view on illness and health, and the related construction of recovery, as a process or on a continuum, as opposed to viewing illness and health as dichotomous constructs (Leader, 2012). My personal position on illness and health regards all persons as somewhere on a spectrum of health. This position helps me to think less of categories of "them and us" (Richards, 2010, p. 40) and more of *all of us* and this, in turn, made a difference in the way in which I tried to approach the participants in my study. This does not mean that I was a perfect researcher, always able to approach my participants perfectly in the way I thought about or interacted with them, but it did make me more aware of where I was in my subjective experiences. I regard service users as individuals, first and foremost, who should be treated with dignity, equality and respect and who should be regarded as being able and placed in a position to make their own choices, as far as is possible, concerning their welfare. This is aligned with the spirit of recovery, which emphasises the individuality and empowerment of persons and their abilities (Deegan, 1988).

Epistemological and ontological positions should also be closely linked to the research strategy within a study. This study employed a mixed-method research design, which leaned somewhat more towards the qualitative side with minor quantitative elements. For a more detailed discussion of the mixed-method design of the study, see section 3.1. on the research design in Chapter 3. The mixed-method design of the study allowed the observation and understanding of the study topic from various perspectives. I used qualitative, a mixed-method and quantitative data collection methods, which suited the exploratory nature of the study of the understanding of mental health recovery and the development of a measure of recovery in a South African context. This aligned with my view that social phenomena, such as mental health recovery, can not only be understood from one perspective or through one research method alone. I acknowledge my role, as researcher, in

the production of the data in this study and as such I believe the data, and consequently the results, are a function not only of what participants contributed to the research process, but also of the interaction between me, the participants and the data. This aligns with my interpretivist epistemological position.

2.2.2. The CHIME framework (Leamy et al., 2011)

In deciding on the theoretical framework to guide the interpretation of the analysed data in this study, I considered two theories. I explored the conceptual model of recovery by Jacobson and Greenley (2001) and the CHIME framework by Leamy et al. (2011). I considered the theory of Jacobson and Greenley (2001), since it is used as a theoretical basis by one of the only truly recovery-oriented programmes in South Africa, The Spring Foundation (n.d.) in the Western Cape. In their conceptualisation of recovery, The Spring Foundation aims to promote recovery by "finding hope for recovery through re-connection" through their programmes (The Spring Foundation, n.d.). The CHIME framework was considered, since it has been widely applied in the field of recovery to conceptualise recovery in various settings and has been well scrutinised (for examples see, Brijnath, 2015; Piat et al., 2017; Van Weeghel et al., 2019).

The conceptual model of recovery devised by Jacobson and Greenley (2001), as indicated in section 2.1.1.9. and 2.1.1.10. earlier in this chapter, consists of internal factors, related to the individual process of recovery, i.e., lived experience and inclinations, and external factors, oriented towards and thus conducive to recovery, i.e., environment, services and policies. According to Jacobson and Greenley (2001), in promoting recovery, both these internal and external factors must be addressed and supported. The internal factors that they identified are (a) hope (possibility of recovery); (b) empowerment (self-determination, fearlessness and taking charge); (c) healing (self separated from disease and control); and (d) connection (social involvement as well as a bridge between internal and external factors)

(Jacobson & Greenley, 2001). The CHIME framework by Leamy et al. (2011) is a much later model than that devised by Jacobson and Greenley (2001) and consists, amongst others and as indicated in section 2.1.1.10. earlier in this chapter, of "recovery processes", namely "connectedness", "hope and optimism about the future", "identity", "meaning in life" and "empowerment" (reflected in the acronym CHIME) (Leamy et al. (2011, p. 448). The two models have much overlap, both referring to hope, empowerment and connection (or connectedness), although the specific content of the factors or processes might differ. However, the CHIME framework (Leamy et al., 2011) refers to meaning and identity, as opposed to healing only in the Jacobson and Greenley (2001) model, which, in my opinion, gives the CHIME framework a stronger alignment with the meaning of personal recovery as discussed in section 2.1.1.8 and as such, with my own alignment with personal recovery. This, as well as the more recent, wide application of the CHIME framework, supported my selection of the CHIME framework as my theoretical framework of choice.

Furthermore, I considered criticisms in the literature levelled against the CHIME framework. From the ranks of its own developers, in reporting on it, it was stated that the framework did not sufficiently represent minority ethnic groups in the context of development (the UK) (Leamy et al., 2011). In a validation study of the CHIME processes in the UK, again from the ranks of the developers of the CHIME framework themselves, Bird et al. (2014) concluded that additional processes might have to be added, such as "practical support", "issues around diagnosis and medication", and "scepticism surrounding recovery" (p. 650), depending on the research context or specific study population. In 2012, some of the researchers that conducted the systematic review and narrative synthesis, which generated the CHIME framework (Leamy et al., 2011), re-visited the systematic review and narrative synthesis and concluded that the CHIME framework is valid, however, it would be necessary to extend research of the framework in other cultures and populations than the English-

speaking world from which it was generated (Slade, Leamy, et al., 2012). Stuart et al. (2017), in discussing the CHIME framework as part of their systematic review of 15 articles on the topic of experience of recovery for service users, suggested adding another dimension, namely difficulties to the framework, in a new so-called CHIME-D framework. Ellison et al. (2018), in their systematic review of the definition of recovery, which included the CHIME framework, criticised the literature, and, by implication, the CHIME framework, for not including culture as a dimension of recovery. Although the scoping review of systematic reviews and meta-analyses of Van Weeghel et al. (2019) summarised the criticism against the CHIME framework for not emphasising challenges and cultural dimensions of recovery, they still acknowledge the importance of the CHIME framework in the literature. Despite these criticisms, which I bore in mind during interpretation of the analysed data, I still considered the CHIME framework suitable as a theoretical basis for this study.

Therefore, I used the CHIME framework (Leamy et al., 2011) as a guide to assist me in the interpretation of the analysed data, particularly the qualitative interviews and focus groups. The systematic review of 97 studies on the descriptions of personal recovery, employing a narrative synthesis of 87 studies, led Leamy et al. (2011) to arrive at their framework of personal recovery. The conceptual framework of recovery is classified into three groups, namely “characteristics of the journey of recovery”, the previously mentioned processes of recovery, as well as stages of recovery. Regarding the details of the processes of recovery, “connectedness” comprised (a) “peer support and support groups” for service users; (b) “relationships”; (c) support provided by various persons in the environment of the service user; and (d) the service user engaging within their community. “Hope and optimism about the future” contained (a) believing in recovery possibilities; (b) having the “motivation to change”; (c) having relationships that support hope; (d) thinking positively and wanting to be successful; and (e) dreaming and aspiring. The third recovery process was “identity” and

constituted (a) aspects of identity; (b) reconstituting a sense of self that is positive; and (c) conquering stigma. The process, "meaning of life", involved (a) what the experience of a mental illness means; (b) "spirituality"; (c) "quality of life"; (d) life and social objectives that have meaning; (e) life and social capacities that have meaning; and (f) putting together one's life. The last, and also the process that was identified the most in the studies included in the narrative synthesis, was "empowerment", which was made up of (a) one's own responsibility; (b) power over one's life; and (c) emphasis of strong points. (Leamy et al., 2011, p. 448).

I found it useful to compare the results on the understanding of recovery in this study with the described processes in the Leamy et al. (2011) framework. The comparison was used to explore the similarities and differences between definitions of recovery in other, international settings and this local setting and informed the development of the definition of recovery and the recovery measure itself. For more detail on the application of the CHIME processes in this study see sections 3.3. on the interviews and focus group discussions, 3.4. on the analysis thereof and 3.7.1. on item development in Chapter 3, as well as the manuscript on the perceptions and understanding of recovery for service users, carers and service providers from a South African perspective in Chapter 4.

2.3. Summary

In this chapter I gave an overview of the literature relevant to the study by firstly exploring the understanding of recovery in the international literature. I drew a distinction between personal and clinical recovery, the latter including remission, as well as between personal recovery and selected rehabilitation concepts. I continued by describing psychological, functional, social and relational recovery as well as resilience as a related recovery concept. Personal recovery, as the version of recovery I align myself with most and the basis for my approach in this study, was examined in more detail to conclude this section.

To examine recovery in context, I explored some barriers and facilitators to recovery thereafter. I then proceeded with an overview of the history of modern conceptualisations of recovery, followed by a broad description of the study context, South Africa overall, and, the Western Cape, more specifically. I also described public mental health care service users, recovery and some of the recovery-oriented programmes that exist in South Africa. To conclude the literature review, I investigated the existing instruments to measure recovery, where the measurement of recovery in South Africa currently stands and some issues that might impact thereon.

In the second part of the chapter, I discussed the theoretical framework I applied in relation to my position as researcher, that is, my ontological and epistemological position in this study. I also discussed my views of mental health and illness. I linked this with my research strategy.

Further, I identified the two theoretical frameworks that I considered for interpretation of the analysed data in the study and justified my choice of the recovery processes in the conceptual framework by Leamy et al. (2011) that ultimately formed the theoretical framework by considering the criticisms against it.

Chapter 3: Methodology

In this chapter I discuss the research methodologies used throughout the study. I, firstly, focus on describing the aim of the study and the broad process of data collection and analysis. Next, I describe the research design. Participant characteristics are also reported on and further I elaborate in detail on the different steps during the study. Lastly, I discuss the ethical considerations related to this study.

My aim with this study was to develop a measure for individual recovery from the service users' perspective. In doing so, the first step was to explore various role players' understanding of recovery through interviews and follow-up focus group discussions. Thereafter, the goal was to conceptualise recovery and operationalise it, based on the results from the initial qualitative exploration. The operationalisation of the definition of recovery for the study context was used as a basis to develop a set of questions from which the recovery measure resulted and could be tested for initial content validity.

Since the research design was sequential in nature, i.e., the results from one step in the research process informing the next step and the nature of the PhD study, i.e., by publication, I also include some results in this chapter. Although this is unusual, I believe it is necessary, firstly to form a coherent chapter, otherwise the methodologies would have to be repeated elsewhere with the results, and, secondly, so as not to lose results that could not be reported on in the articles contained in Chapters 4, 5, and 6, due to word limits.

3.1. The research design

I believe that research should be executed by using a research design that best fits the research questions, the type of research and the context in which the research is conducted. In addition, as a researcher, I am most comfortable and experienced in conducting qualitative research, which also fit well with the choice of research design for the study. The research question in this study was best answered by a predominantly qualitative data collection

method, with minor quantitative elements. The larger context in which the research was conducted is a developing context, South Africa, with research of an exploratory nature, mental health recovery, and as such it lent itself well to the in-person involvement of the researcher in data collection, such as provided for by qualitative research. I therefore employed a research design that was predominantly qualitative in nature by including interviews, focus groups and cognitive interviews, which were purely qualitative, as data collection tools. Other data collection tools, however, contained minor elements of a quantitative nature, such as the content validity process of matching measurement items with its dimensions as well as a Delphi panel, which in this study was used as a mixed method, with a balance of both qualitative and quantitative elements. I was also open to be led by the iterative nature of the particular research process and, although I had a research plan at the outset, the plan was open to being influenced by the results of the focus group discussions, Delphi panel and cognitive interviews (Durrheim, 2010).

Thus, to summarise, according to Bryman (2016a) and Doyle et al. (2016), I employed a mixed-method design in the study, which leaned towards an exploratory sequential design, by using primarily qualitative methods initially, but thereafter lesser quantitative methods to elicit further data for analysis, with which I assumed my pragmatic approach to data collection in order to provide a more balanced and rounded data collection effort (Johnson et al., 2007). The exploratory sequential mixed-method design is particularly suited to instrument development studies, such as the present study (Doyle et al., 2016). Hasson-Ohayon et al. (2016) advocate for the use of a mixed-method design in the evaluation of recovery interventions as the concept of recovery is multi-faceted and consists of both subjective and objective aspects. This argument is also relevant to the development of a measure of recovery, as in this study, as it involved both the qualitative process of

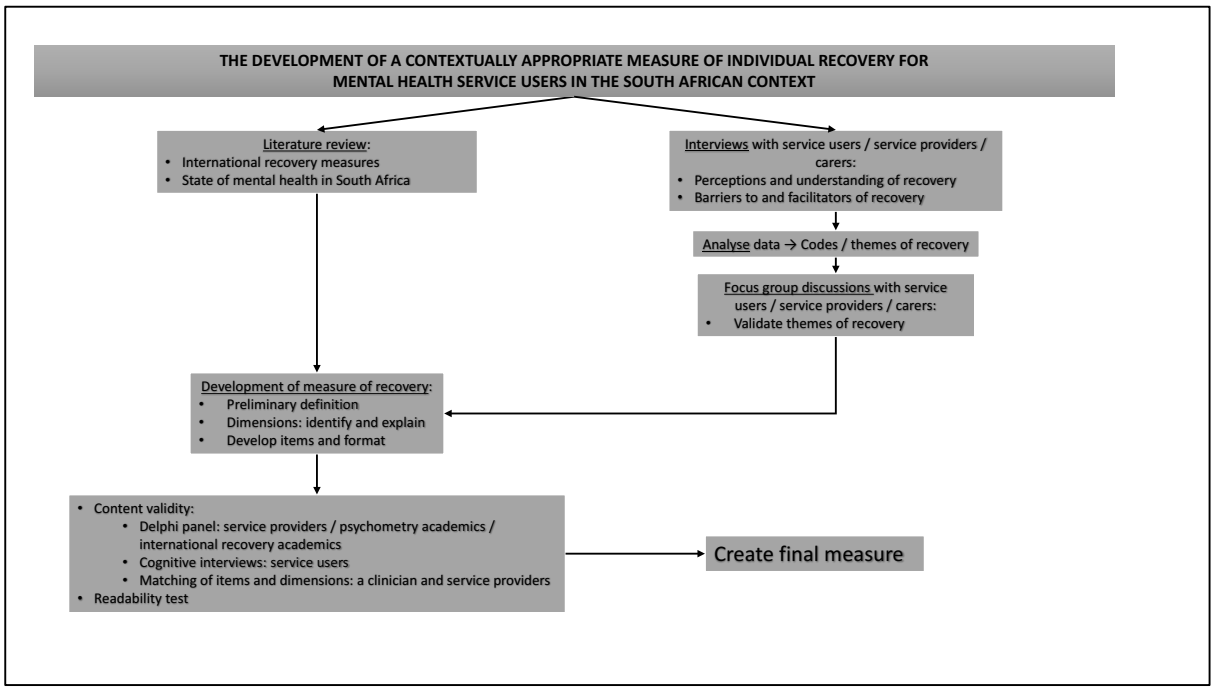
conceptualisation and formulation of a recovery definition and themes as well as the qualitative and minor quantitative aspects in the development of the measure.

Although the mixed method design has been increasingly used, it has also been criticised for its combination of quantitative and qualitative methods, which can be viewed as epistemologically and paradigmatically incompatible (Bryman, 2016a). Despite criticisms, I believe the mixed methods design offers a researcher variance in the combination of ways in which topics can be researched and, given that the researcher's own paradigm is pragmatic, can provide the researcher with a richer result than would be possible by using quantitative or qualitative methods alone.

Figure 3.1 provides a graphic overview of the study, indicating how aspects of the research design were executed.

Figure 3.1

Overview of the Study



3.2. Description of participants

The participants in this study consisted of public mental health service users, carers and service providers, as well as local psychometry academics, international recovery academics and a clinician.

The service users were persons who were primarily faced with extreme financial, housing, employment and social insecurities, i.e., persons who had low socio-economic status, and were to a large extent stigmatised by and, consequently, disconnected from their communities. These service user participants were persons who had spent at least six months in total in one of the tertiary psychiatric hospitals in the Western Cape and were able to communicate well in either English or Afrikaans, so that my research assistant and I could conduct the interviews, focus group discussions and cognitive interviews personally without the assistance of a translator. I did this to ensure that I could obtain a rich description of the participants' experiences and our conversations with her or him were in a language that both participant and researcher understood, in an attempt to minimise misunderstanding. These service user participants were all diagnosed with a chronic and severe psychosocial disability (for example, schizophrenia, bi-polar disorder and schizoaffective disorder) and, while hospitalised, had participated in some form of recovery or psychosocial intervention or programme, available to service users at the hospital at the time. The inclusion criteria for the recovery or psychosocial intervention or programme was wide, so that almost any form of activity that a service user had engaged in at the hospital was acceptable. The purpose of the intervention or programme criterion was to ensure that service users who took part in the study had some form of exposure to information about the importance of taking care of one's mental health in some way, however that might be, and a hopefully resultant awareness that they could share in the interviews, focus groups and cognitive interviews. The service users

took part in the interviews, focus groups and/or the content validity processes of the cognitive interviews.

The carers of service user participants were persons, family members or otherwise, who were involved in the financial or emotional support of, and caring for, service users. The carers took part in the interviews and/or focus groups. These carer participants were persons who were able to communicate well in either English or Afrikaans, once again allowing my research assistant and I to conduct the interviews and focus group discussions personally, without the assistance of a translator, and with minimal misunderstanding.

The service provider participants were service providers who were either directly or indirectly involved in the provision of services, interventions and programmes to the service user participants. The service providers took part in the interviews, focus groups and/or content validity processes, namely the Delphi panel and/or the matching of measure items and dimensions.

The three local psychometry academics were affiliated to South African universities and experienced in the development of measures. They contributed to the development of the measure in this study through expert advice or the content validity process of the Delphi panel.

The two international recovery academics contributed to the development of the measure by taking part in the content validity process of the Delphi panel. Both had extensive experience in recovery research. They had specifically relevant experience, amongst other expertise – the one academic in the development of a recovery measure and the other in qualitative recovery research within marginalised groups.

A clinician, who was also an academic, took part in the content validity process of matching the measure items with its dimensions.

The hospitals that were the sites for the collection of data were public tertiary psychiatric hospitals in the Western Cape. The hospitals served as access points to service user, carer and service provider participants for me as researcher. The hospitals themselves, however, were not the focus of this study, since the goal was to develop a measure of individual recovery and not a measure of the recovery-orientation of health care systems.

Table 3.1 provides an overview of participants in the study.

Table 3.1

Participants in the Study

Cohort of participants	Number of participants (n = 45)	Stage of data collection participated
Service users	14	Interviews (13) Focus group (3) Content validity: Cognitive interviews (4)
Carers	12	Interviews (12) Focus group (3)
Service providers	13	Interviews (12) Focus group (3) Content validity: Delphi panel (2) Content validity: Matching of items and dimensions (5)

Local psychometry academics	3	Expert advice (1) Content validity: Delphi panel (2)
International recovery academics	2	Content validity: Delphi panel (2)
Clinician	1	Content validity: Matching of items and dimensions (1)

3.3. Interviews and focus group discussions

During 2018 and 2019 I conducted a total of 37 interviews and three focus group discussions with service users, carers and service providers across the three participating public tertiary psychiatric hospitals in the Western Cape Province of South Africa.

I was reliant on service providers to identify service users at the hospitals who could potentially take part in the study, because I was, understandably from an ethical point of view, not allowed direct access to the service users, who were mostly in-patient and/or forensic service users. This could, however, mean that service providers identified those service users that would present a favourable view of the mental health services and this could have possibly influenced their views on mental health recovery. This was, however, unavoidable.

Regarding the service providers, I attempted to get as diverse a group of service providers as possible. I interviewed service providers who were involved in the care of service users who participated, or similar service users. I included psychiatrists (2), psychologists (3), occupational therapists and occupational therapy technicians (3), a social worker (1) and nurses (3). This gave me access to differing perspectives of multi-disciplinary team members who worked at the hospitals.

Names of potential carer participants were either sourced from service provider participants or contact persons at the hospitals via email or from service users before or after their interviews.

I conducted the 37 interviews, which were in-depth and semi-structured, with 37 participants to elicit a thick description of the perceptions and understanding of recovery and the barriers and facilitators thereto by the participants.

Table 3.2 presents the demographic information of participants in the interviews and focus groups.

Table 3.2

Demographic Information of Interview and Focus Group Participants

Cohort	Gender (F/M)	Age	Language	Hospital	SU location / SP occupation / C relation to SU	Diagnosis of SU	Participant number
Service users							
	F	30	E	H2	Out-patient	Bipolar mood disorder	1
	M	41	X	H1	In-patient, forensic	Bipolar mood disorder	28
	F	23	A	H2	In-patient, forensic	Schizophrenia	14
	F	34	A	H2	In-patient, forensic	Schizophrenia	19
	M	35	X	H1	In-patient, forensic	Schizophrenia	23*
	M	29	X	H1	In-patient, forensic	Schizophrenia	24*
	M	44	E	H1	In-patient, forensic	Schizophrenia	32*

Service users							
	M	ND	E	H1	In-patient, forensic	Schizoaffective, bipolar type	38^
	M	35	A	H2	In-patient, general	Schizophrenia	2
	M	35	A	H3	In-patient, residential	Schizophrenia	6
	M	47	X	H3	In-patient, residential	Schizophrenia	7
	F	38	A	H3	In-patient, residential	Schizophrenia	8
	M	29	A	H3	Step Up Step Down facility	Bipolar mood disorder	4
	M	29	X	H3	Step Up Step Down facility	Schizoaffective disorder	10
Carers							
	F	59	A	H2	Mother		21
	F	55	E	H3	Mother		22*

Carers							
	F	55	E	H3	Mother		25
	F	61	X	H1	Mother		33
	F	77	E	H1	Mother		34
	F	38	E	H2	Sister		11
	F	55	E	H2	Sister		29
	M	22	E	H2	Son		26
	F	30	E	H3	Niece		20*
	F	21	X	H3	Daughter		18*
	M	37	E	H1	Brother		31
	F	52	X	H1	Aunt		36

Service providers							
	F	58	A	H2	Nurse		5*
	M	28	X	H3	Nurse		12
	M	64	A	H1	Nurse		37
	F	29	E	H3	Occupational therapist		9
	F	36	E	H1	Occupational therapist		27
	F	54	E	H2	Occupational therapy technician		17*
	F	41	X	H3	Social worker		15
	F	ND	E	H2	Psychologist		3*
	M	49	E	H2	Psychologist		16
	F	ND	E	H1	Psychologist		35

Service providers							
	M	ND	E	H1	Psychiatrist		13
	F	47	A	H3	Psychiatrist		30

Note. F = Female; M = Male; X = Xhosa; A = Afrikaans; E = English; H1 = First hospital; H2 = Second hospital; H3 = Third hospital;

* = Participated in both an interview and a focus group; ^ = Participated in a focus group only; ND = Not disclosed.

Of the 37 interview participants, 13 were service users, 12 were carers and 12 were service providers. One service user participant declined to participate but offered no reason. One carer was unable to participate due to time constraints. And, lastly, of the service provider participants approached, three declined to participate, two due to time constraints and the third due to their uncertainty about the value of their contribution. Twenty-two (60%) participants were female. Seventeen (46%) participants were English speaking, 10 (27%) participants were Xhosa speaking and 11 (30%) participants were Afrikaans speaking. Interviews were conducted either in Afrikaans or English, depending on the preference of the participant. Xhosa speaking participants all expressed comfort and proficiency in English and the interviews with them were conducted in English. I used an interview schedule with initial questions related to the perceptions and understanding of recovery as well as barriers and facilitators thereto as a guide for the interview process. The interview schedules for service users, carers and service providers are attached as Appendix C1-C3. The questions for the interview schedules were formulated from my understanding of the theoretical framework that I was using for my research, namely the CHIME framework (Leamy et al., 2011). Essentially, three questions were asked, what is recovery, what helps recovery and what does not help recovery? I used probes such as, *That is interesting, could you tell me more about it?* or, *I hear you say this and this, is that correct? Could you explain some more?* to encourage participants to elaborate more on their responses.

Since the field of mental health recovery in South Africa is still very much in its infancy, the interviews were exploratory in nature to gain a proper understanding of what recovery means to the participants in the study context and how that differs from other, international views of recovery. The exploratory approach of the interviews also results from my initial discussions, before the study, with a clinician at one of the hospitals, that formed part of the study and where recovery programmes were being implemented, during which he

informed me that service users, carers and even service providers might be unfamiliar with mental health recovery as a construct or real possibility. Although I initially intended to conduct 36 interviews, I added one interview with a service user at one of the sites, because one of the initial service user participants was unable to articulate their understanding of recovery and its facilitators and barriers well enough to provide as thick descriptions as I had hoped they would be. I noticed, approximately three quarters of the way through the process of interviewing the participants, that data saturation was slowly being reached in all three groups of participants (Kelly, 2010a). Although new participants contributed some new data, they were starting to repeat the data that I had received from earlier participants. Therefore, I did not interview more participants, other than the extra service user participant that I included during the course of the interview process. The interviews lasted between 33 and 87 minutes each.

Analysis of the interviews, as described under the heading *Analysis of Interviews and Focus Group Discussions* (section 3.4) below, was performed. The ensuing preliminary results from the interviews were summarised and presented in a focus group discussion format to one group each of the three cohorts of participants, i.e., one focus group for service users, service providers and carers. I added one service user participant, who had not taken part in the interviews, to the service user focus group. This additional participant met all inclusion criteria for service users. I included this additional service user participant because only three of the service users from the interviews at the hospital were available and willing to take part in the focus group (Kelly, 2010b). The same type of questions as were used in the interviews, were used for the focus group discussions to validate the interview data and resultant themes. The focus group interview guide is attached as Appendix C4. The three focus groups lasted between 52 and 93 minutes each. The initial themes as well as facilitators and barriers to recovery from the interviews were confirmed through analysis of the focus

group data. The focus group discussions provided a forum for the interaction between group members, which offered me valuable additional data to the already collected data from the interviews (Kelly, 2010b). Although I had hoped for a minimum of four participants in each focus group, the carer and service provider focus groups consisted of only three participants each, since it proved to be difficult and time consuming to engage more participants and arrange for all to be together at the same time and place than initially anticipated.

A research assistant, whom I trained specifically for these purposes, assisted with the focus groups. Although the number of participants for the focus groups were small, I wanted someone to attend the focus groups as an observer to pick up on cues and behaviours of participants that I might miss while my attention was focused elsewhere in the group. The assistant was a Master's graduate in psychology with experience in qualitative data collection and was in the process of starting her own PhD study, so I regarded her as adequately skilled to assist me in this task. Not only did she observe, but she also took notes which freed me up to focus on the facilitation of the group process (Kelly, 2010b). Through these focus groups the participants were involved in the research process to ensure a basic participatory action research approach (Bhana, 2010), that an iterative process was followed in developing the recovery measure and, lastly, to ensure the appropriateness of the recovery measure for the context.

3.4. Analysis of interviews and focus group discussions

Interviews and focus groups were audio-recorded, with all participants' consent. The data were analysed using Atlas.ti (Atlas.ti, Version 8.4.4) (Atlas.ti Scientific Software Development GmbH, 2018), a qualitative data analysis software programme, and with thematic analysis as described by Braun and Clarke (2006), updated to be referred to as reflexive thematic analysis in a more recent publication by the same authors (Braun & Clarke, 2019). The decision to use reflexive thematic analysis (Braun & Clarke, 2019) was

made in the light of other methods, such as Interpretative Phenomenological Analysis (Smith et al., 2009) and Grounded Theory (Glaser & Strauss, 1967; Strauss & Corbin, both as cited in Mills et al., 2006). It was concluded that the last mentioned two methods were either more suited to smaller sample sizes than in the present study, in the case of Interpretative Phenomenological Analysis (Smith et al., 2009), or too time consuming an endeavour for the extensive scope of the present study, in the case of Grounded Theory (Glaser & Strauss, 1967; Strauss & Corbin, both as cited in Mills et al., 2006). Reflexive thematic analysis is a widely used and methodical tool for analysing data in the social sciences. It can be used across a broad spectrum of topics and is not narrowly prescriptive (Braun & Clarke, 2006, 2019). In this study, it was used to identify the meaning and themes of recovery and the facilitators and barriers to recovery.

I set out the steps I followed to analyse the data, according to Braun and Clarke (2006, 2019), below.

The first step was to transcribe the data and acquaint myself with the data. The interviews and focus groups were transcribed verbatim. I transcribed some of the interviews myself and the remaining interviews, as well as the focus groups, were transcribed by two transcribers. I considered why I was asking transcribers to transcribe the bulk of the data and I came to the conclusion that it was important for me to transcribe some of the interviews myself, since this helped me to immerse myself in the data initially. Having the rest of the interviews and the focus group discussions transcribed by transcribers, however, freed me up later in the process to focus on conducting the interviews and focus groups without being burdened with the looming transcriptions and the thought of having to transcribe the data myself, which could have influenced me to limit the length of the interviews or focus groups. It also helped focus my attention during the analysis process solely on the analysis and not on the, in my opinion, stressful and tiring process of transcription. Once I received the

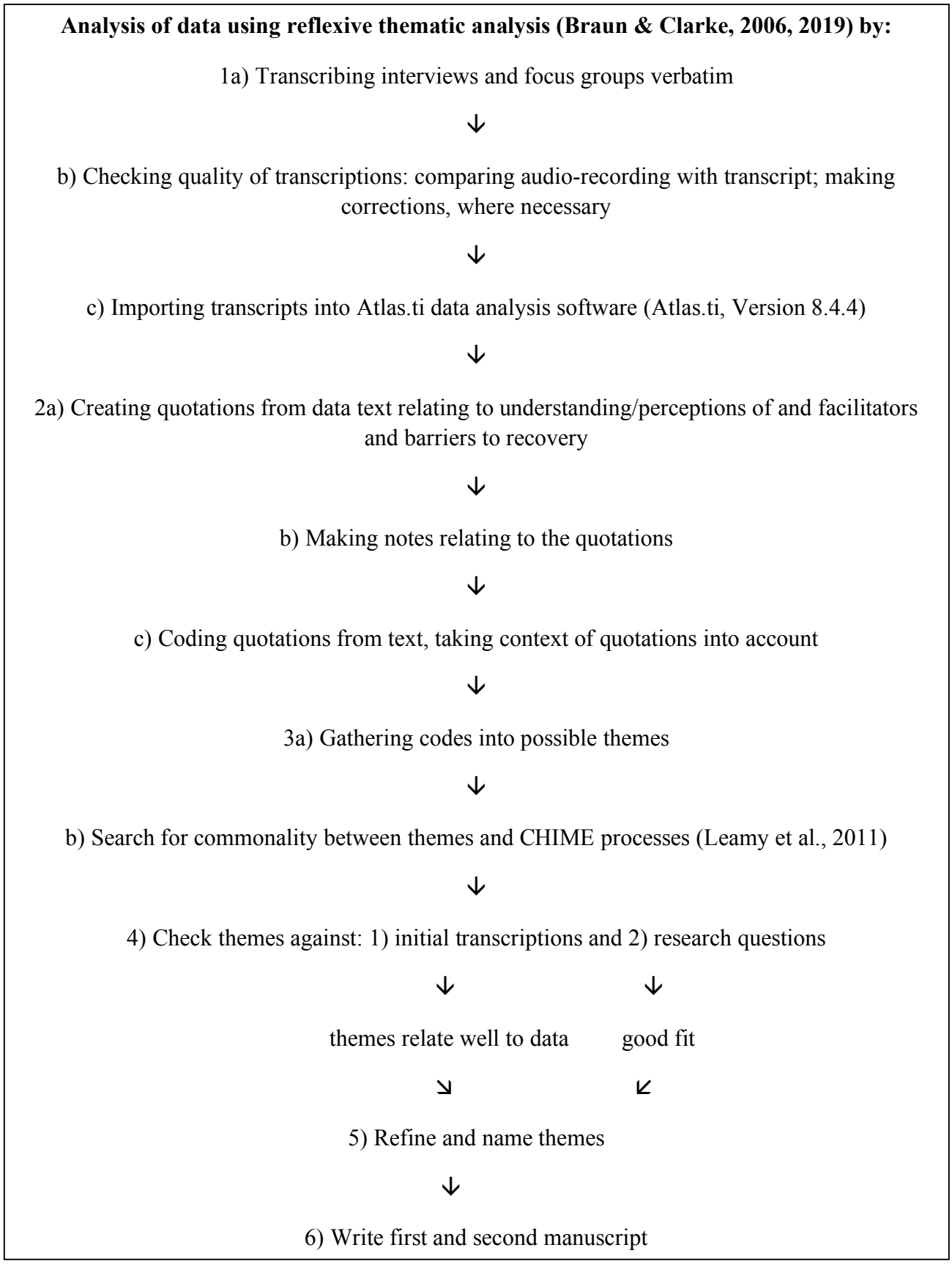
transcriptions, I read the copy while listening to the corresponding recording to verify the accuracy of the transcriptions. I made changes where necessary to improve the accuracy of the transcriptions. Thereafter, I listened to the recordings of the interviews and focus groups repeatedly, while reading the transcriptions in order to immerse myself in the data. I also read and re-read the transcriptions to fully acquaint myself with the data. During the process of reading and re-reading the transcriptions, I started with the second step in Braun and Clarke's (2006) guidelines for thematic analysis by highlighting relevant quotations from the data that related to the understanding of recovery, its facilitators and its barriers. I made these highlights and then made notes related to these highlighted sections in Atlas.ti. By making these notes, I started to generate initial codes, as Braun and Clarke (2006) require in their second step. I contemplated the whole of these codes once I had completed this step with all the interviews and focus groups, to see what the general trend of the codes were. The next step was to gather these codes into possible themes. The use of Atlas.ti makes this step considerably easier than by hand, by keeping a record of where each code comes from in the data set and making it possible to trace codes that have been made part of themes, back to the source document easily. Whereas the initial part of the analysis was a bottom-up approach, I also compared the themes generated from the data with the CHIME processes (Leamy et al., 2011) in a top-down approach at this stage. By returning to the source documents and checking that the possible themes that I had identified suited the data, I reviewed the themes and started to generate a structure for the analysis, as required by Braun and Clarke (2006) in their fourth step. At this stage I ensured that the themes were a good fit for the relevant research question. In this way, considering the themes in relation to the original data, research question and the CHIME processes (Leamy et al., 2011), I verified that the direction I was taking with the themes were in line with my research design and theoretical framework. Next, as step five of Braun and Clarke's (2006) guidelines, I had to refine and name the themes.

This meant, as Braun and Clarke (2019, p. 1) state, that I had to not just provide a "summary of data domains" but rather "fully realised themes". This required me to reflect not only on the data set as a whole and the generated themes and relevant sub-themes, but also on the literature, especially Leamy et al. (2011), to determine where the overarching patterns that I was generating from the data set were coming from, in order to name these themes meaningfully (Braun & Clarke, 2019). The first and second manuscript, contained in Chapters 4 and 5 of this dissertation, respectively, provide the report of the results of this process and the sixth and last step in the thematic analysis guidelines set out by Braun and Clarke (2006).

Figure 3.2 is a graphic description of the interview and focus group analysis process using reflexive thematic analysis.

Figure 3.2

Interview and Focus Group Analysis Process



3.5. Evaluation of research process for interviews and focus group discussions

It is important to ensure the quality of the research process followed and the ensuing data generated (Bryman, 2016c). Lincoln and Guba (1985) set out guidelines for determining the quality of the qualitative research process, such as in the case of the interviews and focus groups in this study. Guba and Lincoln (1994) suggest using trustworthiness and authenticity.

3.5.1. Trustworthiness

Trustworthiness entails *credibility, transferability, dependability* and *confirmability* (Bryman, 2016c, p. 302). Each will now be discussed in relation to my interview and focus group research process in this study.

3.5.1.1. Credibility

This aspect of trustworthiness correlates generally to validity in quantitative research (Bryman, 2016c). Credibility refers to the assessment of whether the interpretation of the qualitative data by the researcher is accurate, according to the participants. I determined credibility in this study by presenting the results of my interpretation of the interviews to participants in the focus group discussions. I did this by posing similar questions in the focus groups as I had done in the preceding interviews and presenting a summary of preliminary findings from the interviews to focus group participants. This was to ensure that my interpretation of what the participants contributed in the interviews was a true reflection of their understanding of recovery and its facilitators and barriers. This technique is also referred to as respondent validation and is not without criticism, in that the comments by focus group participants on their own contributions cannot truly validate the findings from one's research (Silverman, 2017) and focus group participants may fail to be critical if they are partial to the researcher or react defensively if the results are not complimentary to them (Bryman, 2016c). However, Silverman (2017) does admit that a focus group adds useful data to the research. In my study a relationship did not develop between myself and the research

participants, since I only interviewed each participant once and was independent of the institutions where they resided at the time. The preliminary results were presented in the focus groups in a neutral way that did not single out specific participants and so was not likely to elicit a defensive response from the participants.

3.5.1.2. Transferability

This aspect of trustworthiness correlates generally to generalisability in quantitative research (Bryman, 2016c). Transferability is the requirement of qualitative researchers to provide as much information regarding the research process as possible, for an audience to make a judgement as to the applicability of the findings to any other space or time (Bryman, 2016c). In this study, I have provided as much information in this section on the qualitative research and the rest of the chapter on methodology as possible to provide the reader with a rich and full picture of the research process. I also kept a qualitative data collection journal during the process of interviews and focus group discussions. The journal is attached to this dissertation as Appendix C5. The journal adds to the richness of this section in the chapter.

3.5.1.3. Dependability

This aspect of trustworthiness correlates generally to reliability in quantitative research (Bryman, 2016c). Dependability refers to a process, as termed by Bryman (2016c), of keeping an "audit trail" (p. 303), which requires the researcher to keep meticulous records of the qualitative research process and then present these to peers to scrutinise and provide feedback. Because of large amounts of data in qualitative research, this can be a cumbersome process and place much pressure on peers, therefore this technique is not often used (Bryman, 2016c). In this research, I have kept records of the qualitative data collection process and asked my supervisor to read through these and provide feedback. The feedback has been helpful to me in reflecting on the way in which I collected the data and how I reported on the

collection process. I regard the drafting of the methodology chapter and my supervisor's checking of the drafts as part of this process.

3.5.1.4. Confirmability

This aspect of trustworthiness correlates generally to objectivity in quantitative research (Bryman, 2016c). With confirmability, it is necessary for the researcher to show that she was not subjective or influenced by her worldview or personal opinions in such a way that it had an adverse effect on the interpretation of the data or how she proceeded with the collection process (Bryman, 2016c). Of course, it is important to note that subjectivity or personal influences on the research process is inevitable. As mentioned earlier, I kept a journal of the qualitative data collection process as it was important for me to remain aware of my own perceptions, thinking and behaviours during the qualitative data collection process and how these impacted on my interaction with the participants. This journal is part of the reflexive process that I followed as the researcher while gathering the qualitative data. Reflexivity is an important aspect of qualitative data collection and contributes to the confirmability of the data (Lincoln & Guba, 1985). During my regular reporting to my supervisor I asked her to read through the journal which meant that she could point out any subjectivities that emerged from it and might have negatively influenced the research. I also discussed my data collection and analysis process in detail and as fully as I could with my supervisor, for her to point out any biases that I might not be aware of myself. The dissertation is by publication and as such the feedback from the peer-review process during publication could additionally assist in indicating such biases. Also see section 7.4. in Chapter 7 on Researcher reflections.

Another technique related to credibility and confirmability can be valuable in determining the quality of the data and processes followed to analyse it. It is called triangulation (Bryman, 2016c) and consists of data, investigator, theory and methodological

triangulation (Kelly, 2010a). Triangulation is the technique of using multiple views to verify how you have placed yourself as the researcher in the data collection and analysis process (Kelly, 2010a). I used data, investigator and methodological triangulation in my study. For data triangulation, obtaining data from more than one source and, as with credibility, I involved three cohorts of participants, namely service users, carers and service providers. For investigator triangulation, employing more than one researcher and, as with confirmability, I verified my analysis of the data and my qualitative data collection journal with my supervisor to obtain her opinion on my personal influence on the research process. Methodological triangulation, using more than one method to research the phenomenon and, as with credibility, using interviews and then focus group discussions, verified my findings.

3.5.2. Authenticity

Authenticity is a further means of evaluating qualitative research, although not as regularly applied as trustworthiness (Bryman, 2016c). Authenticity consists of *fairness, ontological authenticity, educative authenticity, catalytic authenticity* and *tactical authenticity* (Bryman, 2016c, p. 303).

3.5.2.1. Fairness

Fairness refers to whether various points of view within the wider social setting of the research were included in the research collection process (Bryman, 2016c). In this study, qualitative data was collected from service users, service providers and carers. As such the three key role-players in the mental health environment were consulted on their views on recovery and its facilitators and barriers.

3.5.2.2. Ontological authenticity

Ontological authenticity refers to whether the research allowed participants a better grasp on their social context (Bryman, 2016c). In this study, several participants indicated at

the end of the interviews that they had not thought about certain experiences and social aspects of mental health and as such their knowledge of these aspects had increased.

3.5.2.3. Educative authenticity

Educative authenticity refers to how the research assists participants in having a greater regard for the viewpoints of other community members (Bryman, 2016c). In this study this criterion was not necessarily met in a wider sense, since the focus of the study was on a very particular topic that did not necessarily include the wider community. However, the inclusion of carers as participants and subsequently conducting a focus group with them in which the preliminary results were presented and verified, created an opportunity for these carers to understand more about the experiences of service users, service providers and other carers.

3.5.2.4. Catalytic authenticity

Catalytic authenticity refers to how the research may move participants to transform their circumstances (Bryman, 2016c). In this study, it is not clear whether any such changes were initiated or made. This would require a follow-up discussion with participants. However, a carer in one of the focus groups did indicate that she would visit the service user mother of one of the other carer focus group participants to support the latter. The same carer participant also indicated the intention to get involved in an existing support group for carers or persons with serious mental illnesses in the area.

3.5.2.5. Tactical authenticity

Tactical authenticity refers to whether the research causes participants to engage in action in their communities (Bryman, 2016c). In this study, two examples come to mind in this regard. The first is that I introduced one of the service provider participants at one hospital to another service provider at another hospital in the study to learn from a programme that was being run at the latter hospital in an effort to replicate a similar effort at

the former hospital to benefit the service users there. This was one of the highlights of my qualitative data collection process. Another example was when one of the service provider participants in their focus group was made aware by one of the other focus group participants of the possibility of including her patients as part of a novel programme at the hospital, which she thought was only open to certain patients.

3.6. Definition of recovery

Before the detailed development of a measure, it is necessary to be certain of and clear about the phenomenon, or latent variable, that will be measured by the measure (DeVellis, 2017). In this study the phenomenon was individual mental health recovery in the Western Cape Province of South Africa. Although individual mental health recovery relates specifically to experiences of mental health service users and data on its understanding could as such be collected only from such mental health service users, data in this study were also collected from service providers and carers of the service users. The reason for including third parties in exploring the understanding of the phenomenon, that is from the perspective of service providers and carers, is because recovery is a relatively new construct, especially in the study setting, and it is also a complex construct. Very little literature on recovery exists in South Africa (see, e.g., Bila, 2019; Kleintjes et al., 2012; Parker, 2012), let alone the specific understanding thereof (see, e.g., Brooke-Sumner et al., 2014; De Wet & Pretorius, 2020b; De Wet et al., 2015; Gamieldien et al., 2020). For these reasons, multiple perspectives were helpful to define the phenomenon more clearly and comprehensively in the study setting. Together with the exploration of the understanding of recovery, I also ascertained the participants' perceptions of what the barriers to, and facilitators of, recovery were. This gave the results more depth and allowed more space for participants, who were not necessarily used to discussing recovery, to expand on their understandings of the phenomenon and for me to probe further, where appropriate, to facilitate such expansion by the participants about

a relatively new and complex phenomenon in the study setting. The themes relating to the understanding of recovery, generated through the interviews and focus groups, provided the basis for defining the phenomenon of individual mental health recovery. The residual themes generated through the interviews and focus groups related to the barriers to, and facilitators of, recovery for the participants. I considered the themes related to the understanding of recovery and developed an overarching dimension (see section 1.4.7 in Chapter 1 for an explanation of the use of this term) of each and linked the most salient sub-dimensions to each dimension from the original codes and themes. From the overarching dimensions, I formulated a definition of recovery for the study setting. One of the dimensions that I developed, *Awareness of difficulties*, linked with the themes related to the barriers to recovery (De Wet & Pretorius, 2020a). Together with the facilitator themes, this added a richness to the understanding of recovery which I expanded further. The steps and results of this process, about the understanding of recovery and formulation of the definition of recovery, as well as the barriers and facilitators to recovery, are reported on in more detail in the manuscripts in Chapters 4 and 5, respectively.

3.7. Development of measure

It is necessary to note that the spirit of the mental health recovery movement is to emphasise the uniqueness of the recovery journey for each service user (Deegan, 1996). When looking at recovery as a unique process, the development of an instrument to measure individual mental health recovery seems to be contrary to this spirit, since the objective with measurement instruments is to generalise a construct and find a way to assess it (DeVellis, 2017). However, if the measure is used in a sensitive and responsible way, it might not only support service users to gauge their own recovery in the moment, but also their recovery process over time. A recovery measure should not be used only as an instrument to determine a composite score from all components of the measure. This could likely have the effect of

discouraging the service user in their recovery journey if they do not *achieve* through a high score. The scores from the different components or items of the measure should be discussed with the service user and the service user should be encouraged to celebrate those scores that are higher and supported in finding ways in which they can adjust those scores that are lower, if those components or items are significant or salient to the individual service user. If the administration of the measure is repeated over time, service users might find useful information from the scores to determine which areas of their recovery they might want to pay more attention to and work on. The service provider who engages with a service user about their score should understand the service user's own goals as well as their environment, in order for the scores to be discussed in that context and the scores individualised. The instructions accompanying some of the existing international recovery measures, for example, the Questionnaire about the Process of Recovery (QPR) (Neil et al., 2009) and Maryland Assessment of Recovery in Serious Mental Illness Scale (MARS) (Drapalski et al., 2012), copies of which can be found in Appendices C6 and C7 and which, together with two other existing measures, formed the starting point for the development of the measure in this study (see section 2.1.8. in Chapter 2 and section 3.7.2. in this chapter for further details on the choice of existing measures), contain references to the importance of the individuality and relativity of the recovery experience. The instructions at the start of the MARS questionnaire refer to "no right or wrong answers" and in the QPR questionnaire reference is made to "Everyone is different…" and "Not all factors will be important to you…" (Appendices C7 and C6, respectively). It is in the same spirit that I attempted the development of the recovery measure in this study.

3.7.1. Item development

I again compared the definition of recovery that I had formulated with the theoretical framework for the study, being the CHIME recovery processes as developed by Leamy et al.

(2011). I found that there were several dimensions of the definition of recovery that mapped in varying degrees onto various CHIME processes. I also found that some additional dimensions to recovery that did not map onto any of the CHIME processes, emerged from the data collected in the study setting. These dimensions were identified as additional to the CHIME recovery processes. I checked each of the identified dimensions, and their sub-dimensions, once again to make sure they fitted the data and research question.

From the definition of recovery, I developed an explanation of each of the dimensions in order to have a more general description of each dimension's significance for service users and emphasise the importance of placing the service user in a central position in measuring recovery. From the operationalised recovery definition, I used codes from the collected data, quotations from participants and a review of existing measures as a basis and developed possible items for inclusion in the measure. I grouped these items in the measure, according to the dimensions and sub-dimensions that I had created. I generated items and formulated statements for items through both deductive, i.e., logical partitioning through a review of existing measures, and inductive, i.e., grouping through interviews and focus groups, methods for the development of items (Swanson & Holton, 2005). Since this study was exploratory in nature, I naturally leaned towards the inductive method. I decided nevertheless to combine it with the deductive method. I had already gathered some sense of the study context through the qualitative data collected from the interviews and focus groups as well as a previous study I had conducted in the same context a few years before (De Wet et al., 2015), so I was able to meaningfully compare what I knew from the study context with the knowledge from existing measures. I generated 63 preliminary items for possible inclusion in the final measure. I discussed the items with my supervisor and a local psychometry academic. The psychometry expert was a professor at the Department of Industrial Psychology at Stellenbosch University, who had extensive experience in the development of

psychological measures. Although the psychometry expert was not familiar with the measurement of recovery specifically, he was able to assist with advice on the development of measures in general and to try and establish clarity of items. Through this combined process I became aware of issues with some of the items, in terms of their wording and abstractness. After consideration of the issues pointed out, I nonetheless decided to retain all the items, at this stage. This allowed the Delphi panel, in a subsequent step in the research process, to consider all the items. I noted the problems arising, and once the Delphi panel was concluded, I adapted the items. In the process of generating items, I generated several similarly worded items in order to have various options of items for the content validity testing and so that it could be decided then which items to retain and which to discard. I discuss the content validity testing in detail in section 3.8. in this chapter.

3.7.2. Format of the measure

I obtained permission from the developers of four existing recovery measures, namely the previously mentioned QPR (Neil et al., 2009) and MARS (Drapalski et al., 2012), as well as the RAS (Giffort et al., 1995, as cited in Corrigan et al., 2004) (see Appendix C8) and the Recovery Assessment Scale – Domains and Stages (RAS-DS) (Hancock et al., 2015) (see Appendix C9), to use their measures as a starting point for the drafting of my measure. Three of the four existing recovery measures were identified during my initial literature review to be sound recovery measures (see section 2.1.8. in Chapter 2 for a detailed discussion) and the fourth, the RAS-DS, I was introduced to by its developer at an international recovery conference in 2019. Subsequently I read the article on the fourth measure, which indicated it to be an advancement on the Recovery Assessment Scale (Giffort et al., 1995, as cited in Corrigan et al., 2004), from which it was developed (Hancock et al., 2015), and thus decided to include it. I considered the lay-out, formulation of items, instructions, length and response scales of these four measures. I chose a five-point Likert scale, used plain English to

formulate the instructions for the measure in this study and worded statements for items in the first person as far as possible. I discussed the preliminary draft of the measure with my supervisor and the same psychometry academic that I consulted during the item development stage and made some slight adjustments to the measure in accordance with their feedback, again noting their suggestions and heeding their advice for the further development stages (such as, readability of measure and ensuring the quality of the draft measure).

I consulted Boateng et al. (2018), DeVellis (2017), Foxcroft and Roodt (2009), Netemeyer et al. (2003) and Spector (1992) on scale construction to confirm and ensure that I adhered to the necessary requirements, as far as was possible for the development stage.

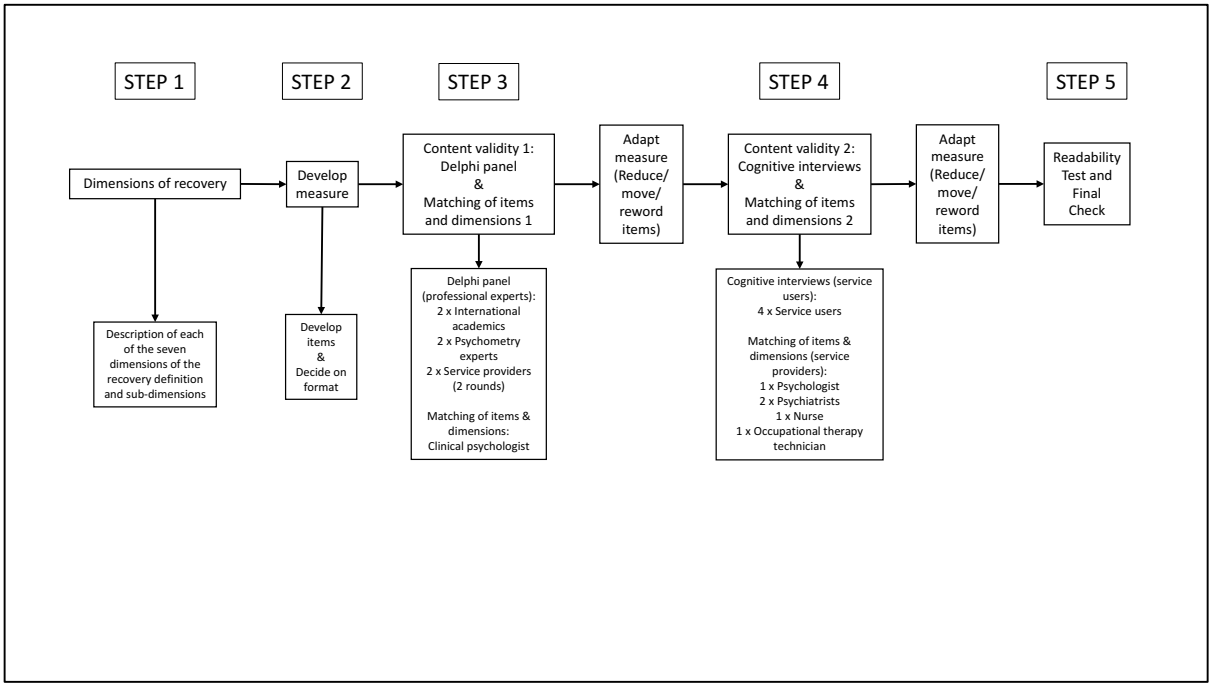
3.8. Preliminary content validity testing

The purpose of content validity is to determine whether the measure will perform what it was constructed to perform (Durrheim & Painter, 2010), in this case to measure individual mental health recovery. Initial content validity was conducted using the Delphi expert consensus method (Jorm, 2015), matching of randomly-ordered items with the dimensions from which they were developed, cognitive interviews (Peterson et al., 2017) and a readability test.

Figure 3.3 illustrates the steps in the process of development of the measure and content validity testing.

Figure 3.3

Process of Development of the Measure and Content Validity Testing



3.8.1. Delphi expert consensus method

The Delphi method was developed in the 1950s in the military field to obtain consensus amongst a group of experts on a particular topic. Several rounds of iteration are held, where group members remain anonymous to each other, and in between the rounds feedback is given to the group members regarding the results of the previous round to facilitate further development towards a final consensus (Bloor & Wood, 2006; Landeta, 2006; Rowe et al., 1991).

The Delphi method was initiated by identifying and approaching six experts to form a panel to advise (Jorm, 2015). Although I was aware of the potential instability of a small Delphi panel (Jorm, 2015), time and a shortage of suitable persons prohibited me from expanding the panel to include more panellists. The Delphi panellists in this study were selected either for their knowledge of recovery or psychometry or, in one instance, both. Of these experts, two were local and two international academic experts. The other two experts were service providers. The panellists were requested to advise on the adequacy of the measure to assess recovery by reviewing the representativeness of items in relation to the

definition and operationalisation of recovery for the study context (Durrheim & Painter, 2010) as well as the appropriateness of the format and structure of the measure for mental health recovery and the technical quality of the measure (Boateng et al., 2018). Their advice was sought with a view to adapt the measure and refine and reduce the number of items to be included in the final measure to be tested. Panellists were provided with general information on the measure and its development, the draft measure, the definition and its operationalisation and a purposefully created review sheet, which needed to be completed and returned to me. See Appendix C10 for the review sheet for round one. To determine the items' representativeness of the definition and its operationalisation, panellists were requested to review each item and decide, in respect of each item, whether to keep or discard that item. This part formed the quantitative component of the application of the Delphi method. This part also formed the main question to the Delphi panel, namely whether the items in the measure are representative of the definition and operationalisation of recovery for the study context. Panellists could also provide comments with their responses on each item. Panellists were also requested to review the appropriateness of the format and structure of the measure by commenting on how the measure was set out overall, ease of instructions, complexity of items and suitability of response choices. Panellists were encouraged to add any additional comments regarding format and structure, as well as comment in general on the measure, including its technical quality or whether the measure is representative and relevant in order to capture the recovery experiences of service users in a South African context. The review of appropriateness, additional and general comments, together with the comments that panellists could provide with their responses on each item, formed the qualitative component of the application of the Delphi method. The comments of the panel on individual items, as well as the feedback from the panel regarding the appropriateness of the format and structure of the measure for mental health recovery, the technical quality of the

measure and any additional or general comments, were used to inform the further refinement of the measure. In respect of the main, quantitative question to the Delphi panel, criteria were set beforehand for inclusion, exclusion and reviewing of items. Jorm (2015), in discussing the use of the Delphi method in mental health research, states that no uniform standard for consensus exists. However, I did set the criteria in my study similarly to those set by Langlands et al. (2008), and followed by Law and Morrison (2014), both being studies employing the Delphi method in mental health research, with the latter in mental health recovery specifically. Thus, if more than 80% of the panellists indicated that an item was to be kept, it was included in the measure and not re-assessed in further rounds of the panel. If less than 50% of panellists decided to keep an item, it was excluded and not re-assessed in further rounds of the panel. Items selected to be kept by between 50% and 80% of panellists were reviewed again in the next round of the panel.

After the first round of the panel, two items were excluded and 37 items were included in the version of the measure directly after the Delphi panel. Twenty-four of the original 63 items from the first round were carried forward into the second round of the panel to be re-assessed. In the second round, panellists were provided with their own feedback (keep or discard), the feedback (keep or discard) from the panel as a whole and relevant comments by all panellists from the first round, without revealing other panellists' identities (Jorm, 2015), in a similar review sheet as for round one. In this way, panellists could consider their own feedback and comments against those of the other panellists and reconsider their own feedback on each item. One panellist dropped out between the first and second round due to his time constraints.

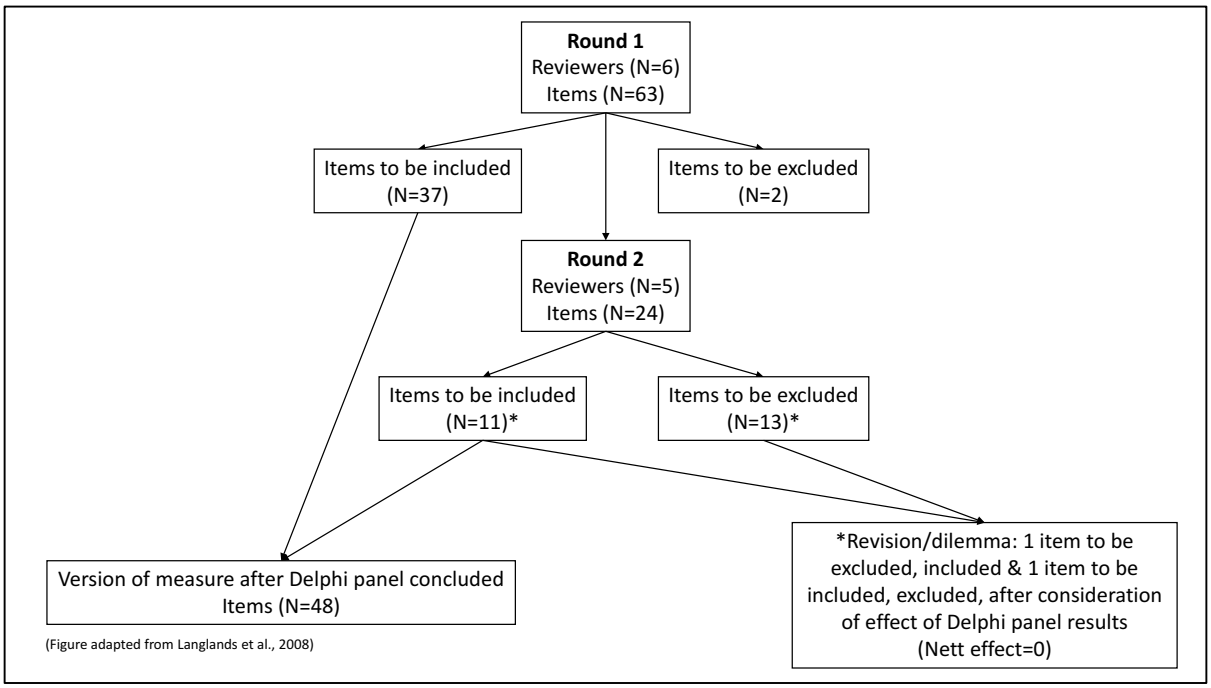
In the second round of the panel, an item had to be kept by 80% of the panel, otherwise it was excluded. Of the 24 items that were carried forward into the second round of

the panel, 11 items were selected by 80% of the panellists to be kept and carried forward into the measure.

Figure 3.4 illustrates the process of inclusion and exclusion of items followed during the application of the Delphi expert consensus method.

Figure 3.4

Process of Delphi Expert Consensus Method



The measure was adapted in accordance with the consensus opinions of the panellists, as described in more detail in the next section.

3.8.2. Matching of randomly-ordered items with dimensions: Part 1

While the Delphi expert consensus process was underway, I requested a clinical psychologist with an interest in recovery to match a randomly-ordered set of the items of the measure with the recovery dimensions and their descriptions (see Appendix C11 for the spreadsheet that was completed). I added this test of content validity at this stage in order to form a preliminary idea of whether the items seemed to relate to the dimensions that I

intended when developing them. The clinical psychologist matched 39 (62%) of the 63 items with the dimensions from which I had originally developed those items. I scrutinised the 24 items that were not matched with the dimensions from which I had originally developed them, to use with the results from the Delphi panel.

I used the results from the matching-of items-with-dimensions exercise and the Delphi panel and the comments from the Delphi panellists and revisited some of the earlier problems identified by the psychometry academic during item development and drafting of the measure (e.g., wording and abstractness) and adapted the measure. Some of the results and problems showed overlap. I adapted the measure through clarification of items (by changing or amplifying the wording of items or making the items more concrete), moving items from one dimension to another, changing the name of one of the response options and adding descriptions of the response options as well as an example statement at the start of the measure. Some examples of the changes that I made to the wording are contained in Appendix C12.

Throughout, I continually discussed the process and results of the Delphi panel and matching-of-items-with-dimensions exercise with my supervisor to ensure that my interpretations of the results were trustworthy, especially regarding their confirmability (Bryman, 2016c).

3.8.3. Cognitive interviews

Cognitive interviewing is a process whereby a small number of respondents are interviewed individually by the researcher to examine the service users' process of thinking about and responding to the items and to determine whether items and response categories are relevant and clear (Peterson et al., 2017). In this study, cognitive interviews were conducted with four service users to determine the suitability and appropriateness of the

measure's instructions, the item content and the format (Boateng et al., 2018; Drapalski et al., 2012).

3.8.3.1. Rationale for cognitive interviews

I conducted the cognitive interviews in this study in order to determine whether the items would be understood by future respondents as intended by me during development of the measure, as well as to determine whether the items were clearly formulated, the response options sufficient and suitable and the overall format of the measure acceptable to respondents (Boateng et al., 2018; Peterson et al., 2017).

3.8.3.2. Preparation for cognitive interviews

Because of time constraints and limited resources, I followed a simplified version of the step-by-step process for cognitive interviewing, as explained in Peterson et al. (2017). I started the preparation for the cognitive interviews by creating a spreadsheet in which I indicated:

1. The dimensions from which each item was derived.
2. The intent behind each item, in other words, which construct the item was intended to tap into.
3. Some "verbal probes" (p. 218) to use during the interviews, should service user participants find it difficult to express aloud their thinking process (the so-called "think-aloud" procedure (p. 218)).

The inclusion of the dimensions, intent behind items and "verbal probes" (p. 218) in the spreadsheet were as per the suggestions in Peterson et al. (2017). See Appendix C13 for the full cognitive interview spreadsheet, used to analyse the results. The "verbal probes" (p. 218) were formulated based on the anticipated relevant cognitive operations, namely

"understanding", "retrieval", "judgement" and "response", as identified by Peterson et al. (2017, p. 219).

I also created:

1. A version of this spreadsheet for my use, as interviewer, during the interviews. This version did not contain the dimensions and provided space next to each item for my interview notes. See Appendix C14 for this version of the spreadsheet.
2. A version of the measure, at this stage, after input from the Delphi panel, the psychometry academic, who advised me during item development, the drafting of the measure and the matching-of-items-with dimensions exercise. This version of the measure contained the full measure with headings, instructions, example and response options with explanations. See Appendix C15 for this version of measure presented to cognitive interview participants.
3. An interview protocol (see Appendix C16), which contained details of the process I would follow during the cognitive interviews.
4. A demographic information sheet, which I had refined, so that I could use it during the cognitive interviews, as a trial-run, and determine whether it was suitable and adapt it, if needed, for future use with the measure. See Appendix C17 for the demographic information sheet.

3.8.3.3. Description of cognitive interview participants

I approached the four service user participants through service providers at two of the three study hospitals. I was unable to identify suitable service user participants at the third hospital due to time constraints and limited access to service providers. The service user participants that I included were persons whom I had included in my interviews and focus groups previously. As such they were familiar with me and my study, which assisted with the rapport between us. I provided each service user participant with an informed consent form

again, since it had been approximately between 12 and 18 months since I had conducted the interviews and focus groups discussions. I also explained my study again briefly at the start of the cognitive interviews to remind the participants. They were reminded that participation was voluntary and choosing not to participate should not affect them negatively at the hospitals. All four participants that I initially approached agreed to participate. Unfortunately, the participants that I could access were all men, so there were no female participants in this stage of the study. One female participant I had identified to include was not available at the time for the cognitive interview. All participants could read and comprehend English, although for some it was a second language. All four participants were in long-term care at their respective hospitals (at least >2.5 years) and they all had been living with a mental illness for at least 11 years, namely major depressive disorder, schizophrenia or schizoaffective disorder.

3.8.3.4. Process of, and feedback from, cognitive interviews

I was very aware going into the interviews that there were 48 items to discuss and that this would take quite some time, given the cognitive interview instructions by Peterson et al. (2017). I found that I was unable to go into depth on every item and, thus, with some items I relied on cues by the participants to gauge their understanding and intent. These cues were, for instance, if participants answered the item easily and gave some context to their answers or did not seem to have difficulty in answering an item. The context that participants often gave me I regarded as part of their "think-aloud" process (Peterson et al., 2017, p. 218) and this helped me to gauge their understanding of the item without necessarily having to make use of "verbal probes" (Peterson et al., 2017, p. 218). I did not want to overburden the service users unnecessarily, so where understanding of a certain phrase or of similar items was already established, I did not go into further details. Where I needed to, however, I did ask

participants what the words that I used in the items meant for them and how they understood the item as a whole. I also enquired from each participant about:

1. The response options (e.g., questions such as, were you able to find your answer from the response options shown?; was there an answer that you wanted to give that was not available in the response options?; were there response options that did not make sense to you?).
2. Their level of comfort in completing the measure.
3. Whether they felt that for some items one of the response options was *the* correct answer to that item (the instructions for the measure refers to there being no right or wrong answers).
4. Their overall impression of the measure.

I received constructive feedback from participants and was able to adapt the measure by eliminating nine items on their recommendation and change the wording of some items to better align my intent with their understanding (and possibly the understanding of the measure's target population as a whole, of which the cognitive interview participants were fairly representative) in order to promote clarity. Although there were only four participants taking part in the cognitive interviews, there were indications of data saturation, for instance more than one participant identified confusion with the same items or regarded the same items as overlapping and in need of elimination. Regarding the format of the measure, I was advised that it would be helpful if the description of each response category was repeated at the top of each page of the measure, in order to make it easier for respondents to refer back to the descriptions while completing each item. I made this change. Participants all agreed that they were able to find the answer that best suited the item for them from the response options given. One participant alerted me to the fact that he was not able to make sense of one of the

response options. I considered his feedback and, in the light of no other such feedback, decided to leave the categories of response options as they were and adapt them, if necessary, after future testing. None of the participants felt that they required additional items to cover other aspects of recovery that might be missing from the measure. I also received constructive feedback on the demographic information sheet from the participants and was thus able to make the items on the sheet more understandable to respondents. It was satisfying to see that the service user participants related to some items in the measure and reacted very positively to them during the cognitive interviews. This gave me an indication that I had translated their interview data into items with meaning for them and hopefully this would be the case for future respondents too.

3.8.3.5. Evaluation of research process for cognitive interviews

As stated before when evaluating the interview and focus group research process, Lincoln and Guba (1985) set out guidelines for determining the quality of the qualitative research process. Guba and Lincoln (1994) suggest using trustworthiness and authenticity.

With regards to trustworthiness (Bryman, 2016c):

1. The credibility of the cognitive interview research process was confirmed by the four participants relating and reacting positively to similar items in the measure during the interviews.
2. Transferability, or a “thick description” (Bryman, 2016c, p. 303), was ensured by the more detailed reflection on my experiences of the cognitive interviews included in the qualitative data collection journal contained in Appendix C5.
3. Dependability, or record-keeping, was ensured by the reporting on this research process for the cognitive interviews in this chapter, to my supervisor during the research process and in the manuscript in Chapter 5.

4. Confirmability, or minimising subjective researcher influences, was ensured by my reflections on the cognitive interviews included in the qualitative data collection journal contained in Appendix C5 and my regular reflections on my research process with my supervisor for feedback from her.

With regards to authenticity (Bryman, 2016c), I had difficulty, due to circumstances, to achieve fairness, since I could only include male service users in the cognitive interviews. Regarding ontological, educative, catalytic and tactical authenticity, I am not certain whether these were achieved through the cognitive interviews, since the information gathered from the cognitive interviews was limited in this regard and, as such, not sufficient to determine what levels of authenticity were achieved.

I once again approached the psychometry academic, who advised me during item development and the drafting of the measure and matching-of items-with-dimensions exercise, and asked him to review the version of the measure once I had adapted it after the feedback from the cognitive interviews. He advised me to simplify items even further, use uniform sentence construction and words where possible, avoid the use of examples in items that might cause confusion for respondents and ensure the coherence between items that form part of a dimension. I refined the questionnaire in line with his advice by re-wording some items to simplify them and make them more uniform, eliminating one item that was very similar to another item and deleting examples within items. He also advised me to once again request the matching of randomly-ordered items with their dimensions. However, this time with a group of service providers from the study hospitals. Although I had not planned this step from the outset, I decided to include it, since I felt that it could contribute significant further feedback on the measure, which could facilitate further refining of the measure.

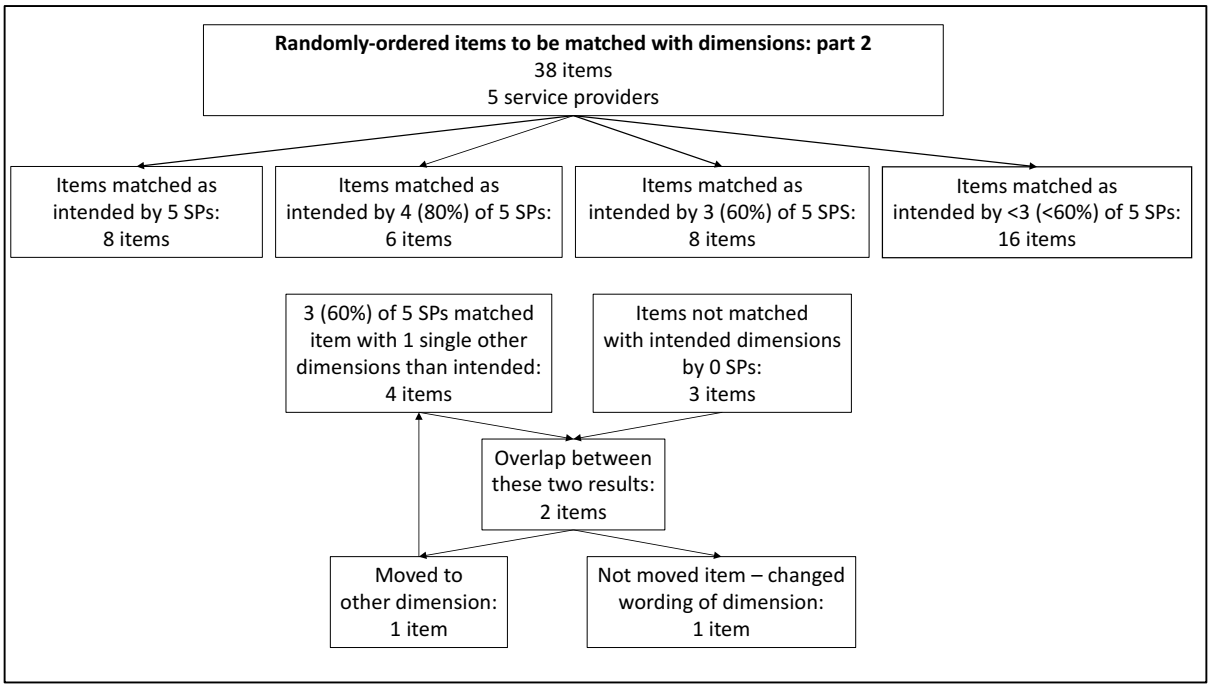
3.8.4. Matching of randomly-ordered items with dimensions: Part 2

I requested eight service providers from the three study hospitals to perform a second round of matching of randomly-ordered items with the measure's dimensions. Five of the service providers (a psychologist, two psychiatrists, a nurse and an occupational therapist) completed the exercise. The other service providers were unable to take part in this exercise due to work commitments. This exercise aided in determining whether an item seemed to service providers, who had extensive experience with service users in the study context, to belong to the dimension I had developed it from or not. Results from the second round matching-of items-with-dimensions exercise are contained in Appendix C18.

Figure 3.5 gives a visual illustration of the second round of matching randomly-ordered items and dimensions.

Figure 3.5

Matching of Randomly-Ordered Items and Dimensions: Part 2



From the knowledge I gained through the second matching-of items-with-dimensions exercise, together with the general trend in the rest of the content validity process, I noticed that some changes could be made to the sub-dimensions of the various dimensions, and their

descriptions. The details of these changes can be found in Appendix C19. The changes to sub-dimensions and descriptions of dimensions are presented in Table 3.3 below.

Table 3.3

Names of Dimensions and Sub-dimensions and Descriptions of Dimensions

Dimen-sion	Name of dimension	Sub-dimension	Description of dimension
1	Relationships with Others	Connection Support Added: Trust	The importance of relationships with others for service users in their recovery process.
2	Moving Positively Forward	Adapt Hope	The wish of service users to move positively forward with their lives and to envision a future for themselves with their mental illness.
3	Relationship with Self	Identity Routine Renewal	The service users' relationships with themselves and (re-)building those relationships.
4	Relating to the World	Purpose Faith Contribution Removed: Insight	The need in service users' recovery process to also relate to, or make sense of their experiences in the world around them.
5	(Re-)gaining of Strengths	Income Independence	Service users (re-)gaining strength to function in the world, despite their mental illness.

		Agency Capacity Removed: Trust	
6	Awareness of difficulties	Challenges and Limitations	Acknowledgement of difficulties, even impossibilities, faced by service users in their recovery process. New: Awareness by service users of difficulties faced in their recovery process.
7	Clinical Understanding to support Personal Recovery	No sub-dimensions	The understanding of recovery by service users in a medical/clinical way. New: The importance of some clinical understanding for service users in their personal recovery process.

3.8.5. Readability test and final check

The final version of the measure was subjected to a readability test. Several studies in South Africa have used tests to determine the readability of various types of texts, such as Grade 4 natural science textbooks (Sibanda, 2014) and health information pamphlets (Joubert & Githinji, 2014; Krige & Reid, 2017). Various commonly used readability tests, for example the Simple Measure of Gobbledygook (SMOG) Index, the Gunning Fog Index, the Flesch-Kincaid Grade Level, Flesch Reading Ease, Linsear Write Formula, Fry Readability Graph, Automated Readability Index and the Coleman-Liau Index exist and have been employed in research (Balogun et al., 2010; Kasule, 2011; Krige & Reid, 2017; Joubert & Githinji, 2014;

Sibanda, 2014). The Microsoft Word functionality, calculating the Flesch-Kincaid Grade Level and Flesch Reading Ease score, has also been employed in research to determine the readability of psychometric instruments to assess attitudes towards HIV/AIDS in young adults in South Africa, the United States and Turkey (Balogun et al., 2010). Krige and Reid (2017) reported that the Flesch Reading Ease and Fry Readability Graph has been used in readability tests for various health texts in English. Sibanda (2014) used an online method for calculating the readability scores on various commonly used readability tests, amongst others the Flesch-Kincaid Grade Level, SMOG Index, the Flesch Reading Ease score, Gunning Fog, the Coleman-Liau Index, Automated Readability Index and Linsear Write Formula (Readability Formulas, n.d.). From the literature, and in particular Krige and Reid (2017), that I consulted, I decided to use a combination of the Flesch Reading Ease score and the Fry Readability Graph to determine the readability of the measure I had developed. I uploaded the full text of the recovery measure, which included the heading, introduction, instructions, response options and descriptions, example statement, items and concluding sentence. The readability scores were 66.4 for the Flesch Reading Ease and seventh grade for the Fry Readability Graph. The Flesch Reading Ease scores from 0 (very confusing) to 100 (very easy). With the Fry Readability Graph the average number of sentences per hundred words and the average number of syllables per 100 words are plotted together and based on the result and Fry's theory, a conclusion drawn about the school grade appropriateness of the text.

Based on the above scores, readability by a person who had received schooling up to the seventh or eighth year was obtained for the measure. Although a very small sample of four, the service users who participated in the cognitive interviews all had some high school, i.e., grade 8 or further, education. Based on this result, I regarded the readability of the

measure as sufficient and no changes were made to the grammar or formulation of text of the measure.

The inclusion of service users and service providers in the preliminary content validation process created diversity in perspectives and expertise and as such it was attempted to address the problem of representation bias that has been raised as a possible issue in respect of the Delphi method in the literature (Bloor & Wood, 2006). Unfortunately, time constraints did not allow me to include the perspectives of carers in this process. I was also pleased and grateful to have included some of the same service user participants in the initial and cognitive interviews. This meant that these participants formed a core group of participants that assisted me throughout the study and I regarded them almost as an advisory board of service users.

Through the preliminary content validation process, the measure was evermore adapted to provide for parsimony, functionality and internal consistency as far as possible (Netemeyer et al., 2003; Spector, 1992). As a final check, I re-read the final version of the measure once again, together with the dimensions and their descriptions. I made sure that, after all the changes that had been made in the steps of the content validity process, items were still included in dimensions that were suitable and that each item in a dimension fitted with the description of that dimension. This was to ensure that the measure was as parsimonious, functional and internally consistent as it could be. Appendix C20 is a table that provides full details of changes to the measure that were implemented through the various content validity stages. The final version of the measure, the Measure of Individual Mental Health Recovery for a South African Context (MIMHR-SA), as I named it and as it would be presented to future respondents, is contained in Appendix C21. The process of development of the measure and preliminary content validity testing (sections 3.7 and 3.8 in this chapter)

formed the final part of the study. The manuscript that reports on the measure development process and content validity testing is contained in Chapter 6.

3.9. Ethical considerations

I obtained ethical approval first from Stellenbosch University's Research Ethics Committee: Human Research (Humanities) (Reference number PSY-2017-1711) (see Appendix C22) and thereafter from the Western Cape Provincial Department of Health (Reference number WC_201801_032) (see Appendix C23). I submitted an annual progress report to both the University's Research Ethics Committee: Human Research (Humanities) as well as the Western Cape Provincial Department of Health and obtained ongoing approval letters (see Appendices C22 and C23, respectively) to continue data collection throughout the study's duration. In the application to the University's Research Ethics Committee: Human Research (Humanities) I referred to a phased ethics process. This meant that I would submit the first version of the developed measure before I embarked on the content validity process. I did so in October 2019 and obtained approval to continue (see Appendix C22). This approval also had to be sought from the Western Cape Provincial Department of Health (see Appendix C23).

Recruitment was initialised through the provincial Department of Health's appointed contact person at each of the three hospitals.

For the qualitative part of the study, I recruited participants by a priori purposive sampling, based on inclusion criteria. This may have influenced the specific service users that I did get access to, because service providers might have wanted to expose me to service users who would provide a favourable image of the mental health services or service providers. I gained access to the carers either via the participating service users or service providers.

I drafted a consent process document for the interviews and focus groups to guide me in discussing the process of data collection with participants (see Appendices C24 and C25 for the consent process document for the interviews and focus groups, respectively). I explained the study to potential participants and offered them the opportunity to ask questions and decline to participate. Participants were made aware of the voluntary nature of their participation and were allowed time to ask questions. Participants were informed that if they wished to withdraw from the study at any point they could do so and were advised that their withdrawal would not have negative consequences for them in the study or as service users. Participants were requested to sign an informed consent form before the interview or focus group (see Appendices C26-C28 for informed consent forms for interviews and focus groups with service users, carers and service providers, respectively). I audio recorded the interviews and focus groups with written consent from the participants.

I also informed participants of the confidential manner in which I would manage the data that I collected from them. Participants' real names and identities were only discussed between me and my supervisor privately. Any participant-identifying references were removed from data that were or will be used, in conference presentations, manuscripts and this dissertation. I also attempted to describe participants in such a way in any of my writings so as not to reveal their identity. The transcribers as well as my research assistant signed confidentiality agreements and transcribers destroyed the audio and transcription files on their computers after sending the transcriptions back to me. I kept their documentation on my computer under password protection and will continue to keep the records for five years after the study has ended, for inspection, whereafter these will be destroyed in an appropriate manner. Any hard copy informed consent forms are safely stored under lock and key.

It was unavoidable for some of the service providers to know the identity of some of the service users, since I was reliant on some of the service providers to provide me access to

the service users. Interviews and the focus group as well as cognitive interviews with service users took place in private spaces, to ensure, as far as possible, that anything that participants shared, remained confidential from other service users or service providers. Their vulnerability, and particularly that of service users in long-term care, was of special importance to me. The interviews and focus group with service providers also took place in private spaces, as far as possible, at the hospitals to ensure confidentiality. The interviews and focus group with carers also took place in private spaces, as far as possible, at the hospitals, with a few at their homes or safe spaces, such as libraries or schools, to ensure confidentiality.

For the content validity process, I explained the study to participants, offered them the opportunity to ask questions and decline to participate. Participants, namely service users, service providers, professional experts (international recovery academics, local psychometry academics and the clinical psychologist) were all requested to sign an informed consent form before their participation (see Appendices C26, C28 and C29, respectively). The data collection activities in the content validity process were not audio recorded. The data collection from the professional experts mostly took place via email with one expert being interviewed in his private office.

I acknowledge and respect the particular vulnerability of the service users and it informed my drafting of any applications for permission or ethical clearance and informed consent forms as well as my conduct with any participant in this study and my writings about participants. I remind myself regularly of the fact that the service user and carer participants were experts by experience and that any study, such as the one in this case, was not possible without their contribution. Psychiatric assistance in the form of an occupational therapist, nurse or psychiatrist was on hand whenever interviews, focus group discussions or cognitive interviews were conducted with service users, to ensure support for participants who might

have felt overwhelmed by the experiences elicited by the research. The need, however, never arose for service users to make use of this assistance. It might seem from this lack of need of assistance that service users may not have experienced the data collection processes as upsetting or evocative and thus requiring assistance. I was also particularly aware of the potential inability of service user participants to concentrate for prolonged periods of time (due to psychiatric medication or illness) during the cognitive interviews and asked participants regularly whether they wanted to take a break. I was also aware of the power imbalance that existed between me and service user or carer participants. Although it was difficult for me to address this meaningfully and to change the imbalance, since I had between one and, at most, three interactions with service users, I did my best to emphasise my independence from the hospitals and tried to assure service users and carers that I would not reveal my conversations with them to service providers. In addition, I also tried to speak in plain English, in order to not speak to service users or carers in a condescending way. I tried to steer away from jargon as much as I could and tried rather to explain terms in everyday language.

I obtained licenses or consents, as necessary, for the use of any existing measures in the study. See Appendices C30-C33 for consents for use of existing measures, RAS, RAS-DS, QPR and MARS, respectively.

3.10. Summary

In this chapter I described the process I followed in this study of collecting data and some of the results from that data collection that informed subsequent steps in the process. The research design was a mixed methods design, in particular an exploratory sequential mixed-method design. I described the participants and how the interview and focus group data collection was conducted. Thereafter, I reported on the analysis and evaluation of the qualitative data collection process. The result of the qualitative data collection and analysis

process was a definition of recovery and I described how I used the definition as a basis for the next step in the study: the development of the measure. I reported on the creation of dimensions and how I linked their sub-dimensions to them from the definition of recovery and from where I developed items and the format of the measure. The last part of the study I reported on was the preliminary content validity testing consisting of a Delphi panel, matching of randomly-ordered items and dimensions over two separate rounds, cognitive interviews and a readability test.

Lastly, I discussed the ethical considerations throughout the data collection, analysis and writing up process.

Chapter 4: Manuscript 1

4.1. Title

Perceptions and Understanding of Mental Health Recovery for Service Users, Carers and Service Providers: A South African Perspective

4.2. Authors

Anneliese de Wet and Chrisma Pretorius

4.3. Focus of the article

In this research article, we report on the findings relating to the meaning of mental health recovery, emanating from the interviews and focus group discussions with service users, carers and service providers in the study. We used reflexive thematic analysis to analyse the qualitative data and generated seven themes with related sub-themes. The seven themes were: 1) Relationship with others, 2) Moving positively forward, 3) Relationship with self, 4) Relating to the world, 5) (Re-)gaining of strengths, 6) Awareness of difficulties, and 7) Clinical understanding to support personal recovery. From these themes, a definition of recovery for a South African context was formulated to inform a next phase of the study. We also discuss the limitations of the study and recommend directions for future research. (De Wet & Pretorius, 2020b).

4.4. Contribution to aims of the dissertation

This manuscript contributes to the dissertation aims by reporting on the meaning of recovery, generation of themes of recovery and the development of a definition of recovery in the study context. These findings enable the subsequent development of a measure of individual recovery for service users in the study context.

4.5. Publication status

As at 21 January 2021, the article, *Perceptions and understanding of mental health recovery for service users, carers and service providers: A South African perspective,* was published in *Psychiatric Rehabilitation Journal*.

4.6. Article

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Perceptions and Understanding of Mental Health Recovery for Service Users, Carers and Service Providers:

A South African Perspective

Anneliese de Wet and Chrisma Pretorius

Psychology Department, Stellenbosch University

Author note

Anneliese de Wet ORCID iD 0000-0002-8121-8698

Chrisma Pretorius ORCID iD 0000-0002-9188-0255

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Correspondence concerning this article should be addressed to Anneliese de Wet, Department of Psychology, Stellenbosch University, Private Bag X1, Matieland, 7602, South Africa. Email: anneliese.dewet@gmail.com

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Abstract

Objective: Understandings of recovery in low and middle income countries, such as South Africa, are still emerging. This study explored recovery understandings by service users, carers and service providers in South Africa. ***Methods:*** Thirty-seven in-depth, semi-structured interviews and three focus groups with service users, carers and service providers from three public tertiary psychiatric hospitals in the Western Cape province of South Africa were conducted in 2018 and 2019. Data were transcribed and analysed, using atlas.ti and reflexive thematic analysis, to generate themes. ***Results:*** Seven themes, with further subthemes, were generated, 1) Relationship with others, 2) Moving positively forward, 3) Relationship with self, 4) Relating to the world, 5) (Re-)gaining of strengths, 6) Awareness of difficulties, and 7) Clinical understanding to support personal recovery. From the themes, a definition of recovery for the South African context was developed. ***Conclusion and Implications for Practice:*** The identified themes were not mutually exclusive - overlap is inevitable when describing personal recovery. These results and definition are informing the second phase of the overall study - developing a measure of personal mental health recovery for the South African context. The results can contribute to the wider clinical, academic and governmental comprehension of recovery, assist in the obtaining or retaining of funding for local recovery initiatives and hopefully be useful for service users to understand their own process of recovery better and to be able to move along in that process. We recommend replicating the study and investigating recovery-conducive environments in South Africa with service users. (250 words)

Keywords: Mental health recovery, South Africa, qualitative, perceptions, CHIME framework

Impact and Implications

Seven themes were generated and a definition of recovery formulated for the South African context. The results can contribute to the wider clinical, academic and governmental comprehension of recovery, assist in the obtaining or retaining of funding for local recovery initiatives and hopefully be useful for service users to understand their own process of recovery better and to be able to move along in that process.

Perceptions and Understanding of Mental Health Recovery for Service Users, Carers and Service Providers:

A South African Perspective

Mental health recovery is a relatively new field of study that started as a formal movement in the Unites States of America (USA) in 1999 (Davidson et al., 2010). Since then, recovery has developed significantly in some high-income countries (e.g. Australian Department of Health, 2009; Canadian Mental Health Commission, 2012; New Zealand Mental Health Commission, 2012; United Kingdom Department of Health, 2011; United States Department of Health and Human Services, 2003). However, understandings of recovery in low and middle income countries, such as South Africa, are still emerging.

The South African context is one of endemic poverty and underdevelopment with underfunding of public mental health services, which are delivered largely on an institutional basis. The context produces challenges, like severely limited financial and human resources, in the South African public mental health system (Jacob, 2015; Kleintjes et al., 2013; Lund et al., 2012; Parker, 2012; Stein, 2014; Sunkel, 2014) and insufficient mental health literacy in the general population (South African Human Rights Commission, 2017), which extends to poor recovery literacy. Furthermore, the connection between mental illnesses and poverty has not been sufficiently investigated and resultantly recognised by the South African government and this shortfall has been cited as contributing to the lack of attention to recovery of service users in governmental policies in South Africa (Kleintjes et al., 2013). The emphasis in public mental health services in South Africa is still very much on symptom relief (Kleintjes et al., 2012) perhaps because of the limited resources and great pressure on service providers to discharge service users as quickly as possible to make space for other service users, which in turn results in 25% of service users being re-admitted to hospitals within 3 months of discharge (Docrat & Lund, 2019, October 9).

Mental Health Recovery: A South African Perspective

Mental health recovery as a value and as part of its objectives, has more recently been included in a South African governmental policy document, the National Mental Health Policy Framework and Strategic Plan 2013-2020 (South African Department of Health, 2013). This policy document provides an imperative for public mental health services in South Africa to be recovery-oriented and recovery programmes to be established (De Wet et al., 2019). Despite the inclusion of the ideals of recovery in the policy, few have been implemented systemically in public mental health services to benefit service users (De Wet et al., 2019).

Psychosocial programmes, aimed at supporting service users through the improvement of vocational or social skills, exist and fulfil an important role in supporting service users, but are not necessarily conceptualised from a recovery approach. Only a few mental health recovery programmes have been developed and implemented in South Africa (De Wet et al., 2019), of which one is offered in the Western Cape province (The Spring Foundation, 2017).

The overall mixed-method study, from which the data reported on here stem, focusses on the development of a contextually appropriate measure of individual recovery for mental health service users in South Africa and is one of the first such studies in South Africa. See De Wet et al. (2019) for further details on the rationale for this study, stemming from an existing recovery programme (The Spring Foundation, 2017).

To develop such measure, we needed a qualitative understanding of recovery for service users, carers and service providers in South Africa. We used the five recovery processes of the CHIME framework (Leamy et al., 2011) as a guide to further analyse the data after our own initial analysis. The CHIME framework was created through a systematic review and narrative synthesis of 97 studies to understand personal recovery (Leamy et al., 2011) and has been applied in various settings (Bird et al., 2014; Brijnath, 2015) and as such

could serve to understand recovery in more settings, such as in this study. We, however, remained open to exploring the participants' views as broadly as possible. The results reported here are the outcome of this qualitative process.

Method

Participants

During 2018 and 2019, the first author conducted 37 interviews and three follow-up focus groups discussions with service users, carers and service providers from three public tertiary psychiatric hospitals in the Western Cape province of South Africa on their perceptions and understanding of recovery. The inclusion criteria and description of the participants are displayed in Table 1 below.

Table 1

Description of Participants and Inclusion Criteria

Participant groups (n = 38[a]: Female = 22; Male = 16)	**Inclusion criteria**	**Diagnoses (service users)** **Relationship to service user (carers)** **Occupation (service providers)** **(with totals in brackets)**
Service users (n = 14: Female = 4; Male = 10)	- English/Afrikaans speaking - Severe/chronic psychosocial disability - 6+ months as in-patient in hospital	Bipolar mood disorder (3) Schizoaffective disorder (2) Schizophrenia (9)

Ages: between 23 and 47 years	- Participated in programme/intervention at hospital	
Carers (n = 12: Female = 10; Male = 2)	Family members or others involved in the financial or emotional support of and caring for service users	Mothers (5) Brother (1) Sisters (2) Son (1) Daughter (1) Aunt (1) Niece (1)
Service providers (n = 12: Female = 8; Male = 4)	Directly/indirectly involved in the provision of services/interventions/programmes to the service user participants	Social worker (1) Nurses (3) Psychiatrists (2) Occupational therapists (2) OT technician (1) Psychologists (3)

Note. [a]Although only 37 persons participated in the interviews, there were 38 participants overall. One additional service user was included in the focus group discussions, due to one of the original interview participants declining to take part in the follow-up focus group.

Regarding the service user participants' inclusion criteria, severe or chronic psychosocial disability was determined by the diagnoses by clinicians in service users' files. Programmes or interventions were broadly as any type of programme run at the hospitals to improve service users' understanding of their mental health.

Procedure

We obtained ethical approval from Stellenbosch University's Research Ethics Committee: Human Research (Humanities) (Reference number PSY-2017-1711) and the Western Cape Provincial Department of Health (Reference number WC_201801_032). We recruited participants by a priori purposive sampling, based on inclusion criteria.

Recruitment was initialised through the provincial Department of Health's appointed contact person at each of the three hospitals, since we were not allowed to approach service users directly. Service providers at the hospitals identified service users who met inclusion criteria. Interviews were conducted by the first author. Service users were interviewed in private spaces at the hospitals. One service user participant declined to participate but offered no reason. We gained access to carers either via the participating service users or service providers. One carer was unable to participate due to time constraints. A time and place for interviews was arranged directly with carers. As the first author met service provider teams at the hospitals, she requested service providers to participate or was referred to potential service provider participants by the contact persons at the hospitals or other service providers. Service provider participants from various disciplines in multi-disciplinary teams were interviewed, to access diverse perspectives on recovery (see Table 1 for occupations of service provider participants). Of the service provider participants approached, three declined to participate, two due to time constraints and the third due to their uncertainty about the value of their contribution.

The study was explained to potential participants, who were offered the opportunity to ask questions and decline to participate. Participants were requested to sign an informed consent form before participation. Audio recording of interviews or focus groups was done with consent of participants.

Interviews were in-depth and semi-structured. An interview schedule was used. Essentially, three questions were asked, what is recovery, what helps recovery and what does not help recovery? Participants were encouraged to elaborate with probes such as, *That is interesting, could you tell me more about it?* or, *I hear you say this and this, is that correct? Could you explain some more?* The interviews lasted between 33 and 87 minutes each. The first author created some rapport with the participants by adapting herself to participants' pace during interviews, emphasising her independence from hospitals and emphasising her interest in participants' recovery process, while being aware of the power imbalance that existed between her and service user and carer participants. Interviews and focus groups were conducted in private spaces at the hospitals, with only a few carer interviews taking place at homes or other suitable community spaces, like a library. Through 37 interviews data saturation was reached.

After initial analysis of the interviews, a summary of the preliminary results was presented to a few participants in focus groups. A focus group was conducted with one group of each of the cohorts of participants, namely one focus group with service providers, service users and carers. A summary of interview results from all the cohorts was handed to each focus group participant. During the focus group discussions, the first author emphasised those results that were salient for the cohort to which the participants in that particular focus group belonged. The focus groups lasted between 52 and 93 minutes each. A purposefully-trained master's degree graduate in psychology observed and made notes during focus groups, which

enabled the first author to focus solely on the facilitation of the discussion. The results from the focus groups confirmed findings from the interviews.

Data analysis

After transcription and quality check, data were imported into atlas.ti data analysis software (Atlas.ti, Version 8.4.4) and analysed using reflexive thematic analysis (Braun & Clarke, 2006, 2019). Data were first analysed and coded fully according to what participants emphasised. Thereafter, we looked for commonality between the CHIME recovery processes, namely connectedness, hope and optimism about the future, identity, meaning in life and empowerment, (forming the CHIME acronym as part of the CHIME framework by Leamy et al. (2011)), and the themes identified from the participant data. Despite an analytic approach that leaned more towards a deductive style, we wished to stay open to themes that could be generated from the data themselves and as such still attempted to be inductive in our approach (Braun & Clarke, 2009). As such our approach was a theory-driven qualitative analysis (MacFarlane & O'Reilly-de Brún, 2012; Moran et al., 2014). An overview of the data analysis process is presented in Table 2.

Table 2

Description of Data Analysis Process

1) Interviews and focus groups transcribed verbatim

↓

2) Quality check transcriptions: compare audio-recording with transcript; make corrections

↓

3) Import transcripts into atlas.ti data analysis software (Atlas.ti, Version 8.4.4)

↓

4) Analysis of data using reflexive thematic analysis (Braun and Clarke, 2006, 2019) by:

↓

a) Creating quotations from data text relating to understanding/perceptions of recovery

↓

b) Making notes relating to the quotations

↓

c) Coding quotations from text by first author, taking context of quotations into account

↓

d) Gathering codes into themes

↓

5. Search for commonality between data themes and CHIME processes (Leamy et al., 2011)

↓

6. Check themes against: 1) initial transcriptions and 2) research questions

↓ ↓

themes relate well to data good fit

Trustworthiness checks:
1) Repeated discussions & further exploration of codes/themes amongst authors: refine results
&
2) Assess credibility of interviews through focus group discussions (Lincoln & Guba, 1985) - analyse focus group data as did interviews: verify and confirm interview results (also known as triangulation (Bryman, 2012)).

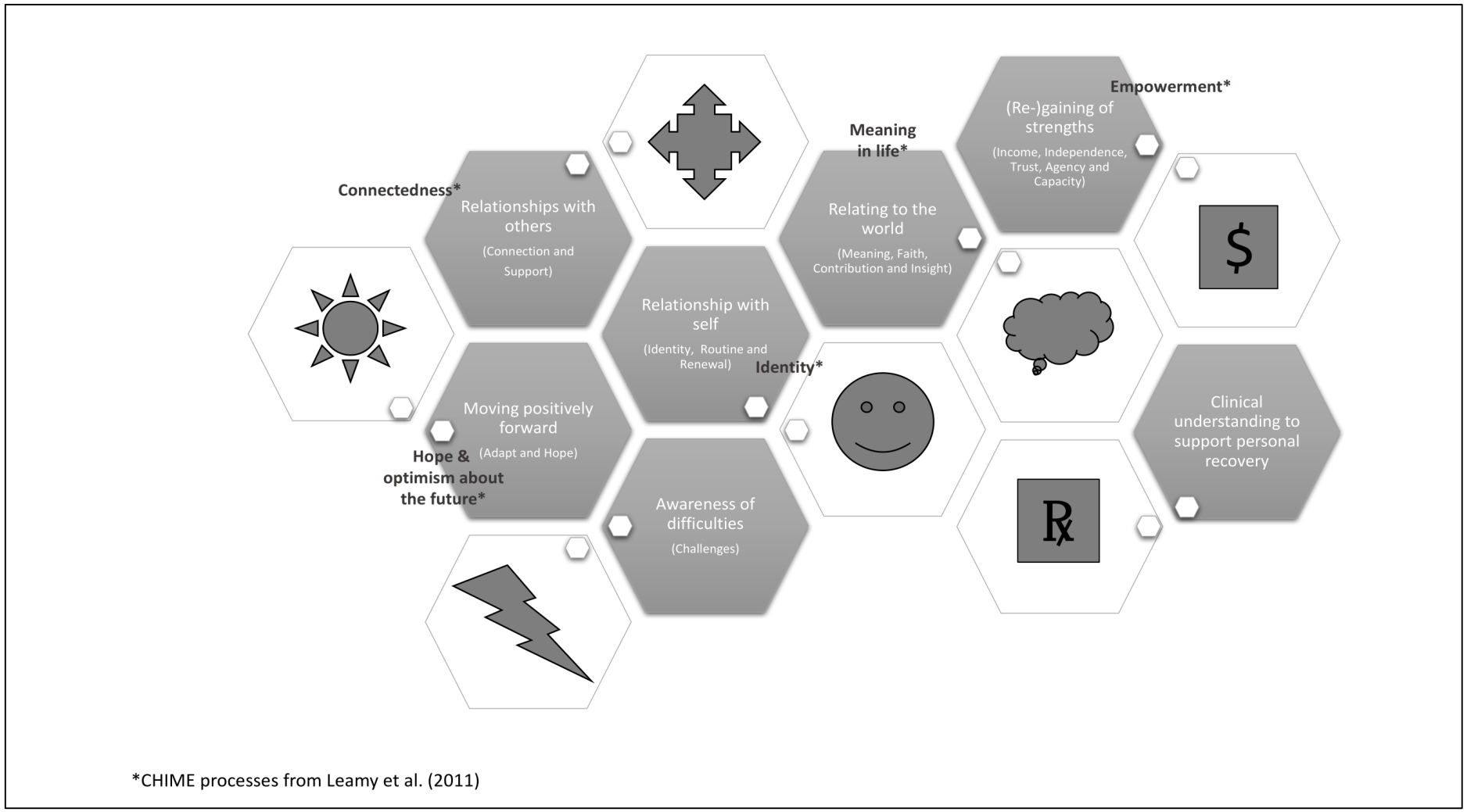
Results and discussion

Overall, participants often indicated that recovery is a process and especially service users and service providers referred to the process being approached collaboratively.

Through the analysis, we identified seven themes of recovery, with subthemes. In Figure 1 we provide a visual overview of the results to be discussed.

Figure 1

Visual Overview of the Results



Relationships with others

Firstly, we generated the theme, *Relationships with others,* consisting of the subthemes, connection and support, which were referred to equally by all groups of participants.

Connection referred to re-connection by service users with family or community, (re-)integration in community or improved general communication by service users. A service user described their process of re-connection with others: "I think I come in contact with people. Started relating with them. They relate with you." (Male service user 1). Another described re-integration into the community as: "…being a person in the community, how you mix in the community. How…umm…become part of the community. I think how you start over in the community." (Female service user 1). Yet another service user described the ability to communicate and get along with others as part of recovery: "…it's like I'm now a person who's is able to communicate with people…" (Male service user 2)

Support referred to service users' connection to carers, understanding by others of service users, others being in touch with service users and peer support. A service provider acknowledged that recovery is rather more about support to service users than complete recovery: "…recovery is a lot more support than it is to get them to really function 100% back at home." (Male service provider 1). Two male service users highlighted, 1) the importance of a support system: "If you had a good support system then you're going to be able to recover…" (Male service user 3) and, 2) peer support: "…inspire them, because you come from the same location, they'll tend to see…ador…idolise you, 'cause you will be a role model by doing so to others." (Male service user 4).

Connection and support seemed to relate to the *Connectedness* process of the CHIME framework (Leamy et al., 2011), which refers to support, relationships and service users being part of their communities (Leamy et al., 2011).

The subthemes of connection and support indicated the importance of relationships with others for service users in their recovery process.

Moving positively forward

The theme of *Moving positively forward* consisted of adapt and hope as subthemes.

Adapt, the subtheme most referred to overall, and fairly equally by all groups of participants, comprised perceptions of recovery as a process of adjustment, change, improvement, moving forward and positivity as well as feeling different, new and better. Acceptance was identified as key to the theme of adapting. Adjustment was an intrapersonal process for service users: "Adjusting to umm… to themselves." (Female service provider 1), whereas another female service provider described it as a process of coming to terms with having a mental illness: "…how they adjust, maybe to having a mental illness" (Female service provider 2). Words like "new person" used by male service user 2 and "better person" by male service user 3 indicated that they perhaps felt a need to change or improve after being diagnosed with a mental illness. Female service user 2, regarded the next step after acceptance as moving forward with the illness by owning, living and dealing with their illness:

> "…I've accepted it now; I have this illness and now I'm going forward with this illness. … I'm accepting it as mine, this is mine now. I have this illness. … Yes, there's a stigma around it, but it's mine. It's something that I have to live with and deal with, so dealing with it is my recovery."

According to female service provider 3, feeling better and being positive went together for service users: "…you're more positive about and you feel, feel better and more positive." Female carer 1 referred to their son being in the process of recovery when "…he's thinking positive…".

Hope, discussed mainly by service providers, was described as:

"…one really essential aspect of recovery, is about trying to instil hope. Promoting that sense that there is something to work towards…There, should be something that you aspire to want, you know? And, and it won't necessarily always come in the package [laughs] you like it to. But maybe there is something that could still be, that you could derive meaning from, and purpose from, despite the circumstances." (Female service provider 2)

The instilling of hope was echoed by other female service providers (1 and 4) as well, as one of the main principles of recovery.

This theme seemed to link to some extent to the CHIME process of *Hope and optimism about the future,* which refers to "belief in possibility of recovery" (Leamy et al., 2011, p. 448), feeling encouraged to change, having role-models, thinking in a positive way, dreaming and aspiring, although the understandings in this context as part of the subtheme of adapt in this theme might be linked more to older, clinical notions of mental illness, which is, in turn, indicative of the mental health context in South Africa described in the introduction and the last two themes generated.

With this second theme participants' emphasis of their wish to move positively forward with their lives and to envision a future for themselves with their mental illness was captured.

Relationship with self

The third theme generated was *Relationship with self*. It consisted of three subthemes, identity, routine and renewal.

Identity referred to self-esteem, citizenship and roles adopted by the service user. Self-esteem and citizenship was referred to more by service providers, like female service provider 2 linking self-esteem closely to identity, and female service provider 5 speaking of the importance of the role of "citizens" and "finding a rightful place in the community", for service users.

Routine comprised of the service users having regained a certain routine. Carers mostly referred to the importance of a routine for service users and female carer 2, a sister of a service user, who lived with them, described and linked it to improvement, "…getting back to what her every day would be and her routine and then, you know, obviously improving that." Male carer 1, linked service users having a routine to being on the way to recovery: "…he's got a routine, you know, and things like that. So, I feel like he's on [his] way to recovery."

Renewal was referred to by all groups of participants, closely related to routine and strongly emphasised as a return to what was before, being again as before, to find oneself again, a sense of being alive, having one's normal pattern back and developing it further. Female service user 3, observed that recovery starts when the acute stage dissipates, "Now my recovery comes when that stage [acute stage] that I was in, when it disappears." Earlier in their interview, female service user 3 elaborated on the theme of routine and said that recovery means building even further on what they could do before: "Not only are you taking part in the things in your life that you did before, you even go further and do things that you did not do before." Female service provider 3 described it as a renewed sense of being alive: "…from the inside you can see and you can see the persons face, the way they carry themselves. You can see everything, there's new life in front of you." Female carer 3 said that service users are in recovery when they return to who they were before they became ill, "…comes back again to the person he was before he became ill."

The CHIME process of *Identity* (Leamy et al., 2011), which consists of the various aspects of identity, dealing with stigma and a positive sense of identity, could be broadly applied to subthemes identity and renewal in this theme.

This theme centred around the service users' relationships with themselves and (re-)building those relationships.

Relating to the world

The next theme generated was *Relating to the world*, which consisted of the subthemes, meaning, faith, contribution and insight.

Meaning, referred to by service users and service providers, related to purpose and satisfaction. Once again as with the subthemes of adapt and hope, acceptance was a precursor to meaning. Female service provider 6 described the progress from acceptance to meaning: "…acceptance of it. Um, so…so, finding the meaning behind it." Female service provider 2 linked meaning to quality of life, purpose, contribution and value: "They can still function and lead a good, umm… quality of life that is, where they have purpose and meaning and, and feel that they contribute to society. That they have value…" Male service user 5, described meaning very succinctly: "…you got to live for sense."

Faith and spirituality were referred to mostly by carers and service users and described the role that religious belief and activities played in recovery. Female service provider 7 described those service users who practiced some form of faith as, "… so those that believe, always have a support community, right? So, umm, they have a place to go to. They have people there that support them." She also stated emphatically that, "I think there is no doubt that if people believe in something, they have a better chance." Male service user 6 in a residential ward described the role of prayer in combatting loneliness for them: "Prayer helps me to say that I am not alone…"

The third subtheme, contribution, referred to mostly by service providers, stood for service users feeling they have value to a community or larger society by being able to go out into their community and fulfil roles. Once again acceptance, but in this case by others, was regarded as a precursor to contributing, as female service provider 5 indicated: "So, if they can accept that, I've got this illness that is within me, I can still live a normal life. I can still be a, a, a productive citizen, a mum and everything else despite having that."

Insight, as the fourth subtheme, referred to slightly more by service providers than service users or carers, comprised acknowledgement (of illness), awareness (of self and signs and symptoms of illness), acceptance (of illness), patience and knowledge. Female carer 4, described recovery as: "That you must be able to recognise that [signs and symptoms of oncoming episode], and go for help. That to me is recovery. Is really knowing your [self/illness], you know?"

The subthemes related in broad terms to *Meaning in life* in the CHIME framework, which refers to what experiencing a mental illness means to the service user, spirituality, wellbeing, having goals and roles that are meaningful to the service user as well as finding ways for service users to live their lives again (Leamy et al., 2011).

Through this theme participants' expression of the need in service users' recovery process to also relate to, or make sense of their experiences in the world around them was encapsulated.

(Re-)gaining of strengths

The CHIME process of *Empowerment* was very well suited to map the theme, *(Re-) gaining of strengths*, which had income, independence, trust, agency and capacity as subthemes, onto. *Empowerment* refers to taking responsibility, mastering one's life and an emphasis on strengths (Leamy et al., 2011).

Income, referred to mostly by service users and carers, consisted primarily of having work or a job that provided income for a service user to be able to provide for themselves or relatives. Female service provider 8 described the importance of income for service users to be able to provide for themselves and contribute: "…they get paid, they get a stipend. So, then he can at least provide for his needs. Buy clothes and make sure there's food, that he can contribute."

Independence, referred to equally by all groups of participants, comprised freedom and taking care of oneself. For male service user 2 independence meant not being a burden to others: "To be able to carry yourself, not to be a burden for somebody…"

Trust, mostly referred to by service users, referred to the service user (re-)gaining others' trust. One service user, being asked by a service provider to perform a task, indicated the crucial building of trust between them and the service provider:

> Male service user 3: Ja [Yes]. Those tasks they [service providers] do give, so it's a good thing for them to do it for me, that.
>
> Interviewer: Yes, it's a skill that you're showing them that you have.
>
> Male service user 3: At the same time building the trust."

Agency, referred to more by service providers than service users or carers, comprised autonomy, responsibility, initiative, decision-making and choice, empowerment and a service user-driven recovery process. An essential aspect was the ability of service users to decide for themselves, as female service provider 3 stated, linking it to planning: "You can make decisions again. You can start to plan again, because that is what you, um, what I see in recovery."

Capacity, mostly referred to by service users, consisted of coping, acquiring skills, being able to deal with challenges, managing and competence. Female service provider 6 made a link between the ongoing presence of the illness, acquisition of skills, living with the illness and understanding self: "…it's not that the mental illness goes away, it's always going to be with me, but I'm going to need to learn skills in order to live with it, to understand it. To understand myself..."

The fifth theme in general relates to service users (re-)gaining strength to function in the world, despite their mental illness.

Although many themes related, in greater or lesser degrees, to the CHIME processes (Leamy et al., 2011), the specific understanding of recovery in this context also generated two additional themes, that did not in any way. These two additional themes are described as *Awareness of difficulties* and *Clinical understanding to support personal recovery*.

Awareness of difficulties

Awareness of difficulties as a theme, included challenges and limitations experienced by participants as part of the recovery process. Female carer 2 explained that their sister, who suffered a setback in their professional career after a psychiatric episode, approached opportunities cautiously after their diagnosis: "…so now-a-days when jobs like that comes up, even though they're great, a great opportunity, she opts for not taking them and she rather opt for something else."

Included in this theme is also the intermittent and iterative nature of the recovery process and service users' awareness of loss. Female carer 1 described their son's recovery as "…on and off."

Awareness of difficulties, as a theme, is to be expected in the challenging socio-economic context in South Africa, which is characterised by high unemployment (Department: Statistics South Africa, 2019), many resource-constraints in public mental health (De Wet et al., 2019) and challenging community contexts, for the majority of the population who are dependent on public health services, and which impacts greatly on their mental health (Schneider et al., 2016).

The CHIME processes make provision for positive and constructive aspects of recovery, but provision for an awareness of difficulties that are often faced in the process of recovery, especially by service users, carers and service providers in resource and opportunity-constrained environments, as in this context, is not clearly included. Van Weeghel et al. (2019) also pointed this out in their recent scoping review of systematic

reviews and meta-analyses of conceptualisations of personal recovery. Van Weeghel et al. (2019) recommended the adjustment of the CHIME framework for differing cultures and suggested adding "Difficulties and trauma" to the framework, similar to what we found by generating this theme from our results.

The context of the study was also emphasised in some of the interviews with the service providers, when they made it clear that they experience great pressure in attending to the large numbers of service users who require assistance at hospitals. Very often, service users who could still benefit from additional support were required to be discharged, to make provision for more acutely ill service users. As such, in step down facilities some more acutely ill service users are accommodated, ahead of those service users for which such services are intended, because of the greater needs of acutely ill service users. This results in the revolving door phenomenon, where the discharged service users, who could have benefitted greatly from additional in-patient care, are re-admitted to repeat the process to subsequent detrimental effects of re-admissions (Docrat & Lund, 2019, October 9).

Awareness of difficulties as a theme in this study refers to difficulties faced by participants in the recovery process and their awareness thereof.

Clinical understanding to support personal recovery

Participants placed great emphasis on *Clinical understanding to support personal recovery*, especially the service user and carer participants. It was the second most referred to theme and overwhelmingly so by service users. Recovery was often regarded as a dissipation of symptoms and remission of illness, by descriptions such as being healed, well or better. The importance of adherence to medication was equally emphasised by participants. Male service user 2, when asked whether recovery is a process, explained it as a process linked to adjusting to and taking medication: "It's a process, yes. You have to go through this to get healthy by using medication, doesn't take on right there, it takes time and your body has to

get used to the medication you get." Recovery was regarded by some as "…getting better completely…". Also, "…complete recovery…" was regarded as a possibility, but not for all service users, as female carer 4 pointed out, "…I don't think he's [service user] done complete recovery. Not in his state. His's more a chronic thing." According to some service providers, it seemed service users found it important to stop taking medication at some point. Female service provider 5 indicated, when some service users were asked what recovery is, they answer: "No, for me recovery is when I don't have to take medication." Yet, male service user 2 indicated that some service providers view recovery as the adherence to medication: "They [service providers] just say take your pills, and you will recover and make sure you take your pills. You eat first and then take your pills. It will help you recover." Unfortunately, some service users stopped taking medication, to detrimental effects, when back in their communities, feeling that they were recovered and because of the stigma associated with mental illness and taking medication.

Clinical understanding to support personal recovery refers to the importance of some clinical understanding for service users to support their personal recovery process.

This final theme correlates with the emphasis by some of the service providers on giving medication, getting the service user stable and discharged. This contrasts with other settings where recovery has developed differently and the emphasis on clinical understanding of recovery is not necessarily as strong (Anthony, 1993; Deegan, 1988). This more clinical approach to understanding recovery was observed, perhaps since recovery is not generally well-known or practised in South Africa (De Wet et al., 2019). It seemed that the CHIME processes (Leamy et al., 2011) did emerge, but were often not the first thought expressed by participants when asked about recovery. But, as interviews progressed and participants were prompted to elaborate on what benefits or what hinders recovery, many of the CHIME processes were alluded to.

Interestingly, correlating with the clinical understanding theme in this setting, a conclusion was drawn in an Australian review of recovery literature by Jacob et al. (2017) that, although many service users conceptualise recovery as a personal process of change, often service users also define recovery by referring to illness, symptom absence or restoration of good health. In Scotland, Chandler et al. (2013) also found that many service users still regard the medical aspects of recovery as important in their recovery journey. As a result, Jacob et al. (2017) repeat the advice of Piat et al. (2017) that harmony should be sought between the personal and clinical views of recovery and that service providers should be open when dealing with differing views of recovery by service users. From our results, this seems to be the case in the South African context too. This would require service providers to acknowledge a wide-ranging definition of recovery, which in turn requires them to be open and accepting of differences in general and acknowledge the possibility of various forms of recovery. Yet, often, circumstances such as scarcity of resources and a high demand on the limited resources that do exist, for instance housing and support upon discharge, undermine such service providers' attitudes (Jacob et al., 2017), the recovery process for the individual service users (Onken et al., 2007) and often thwarts the recovery-oriented efforts of service providers.

From the results, it is evident that the identified themes are not mutually exclusive and that overlap exists. Such overlap seems inevitable when describing personal recovery. The themes of recovery are closely linked to each other and, for example, as indicated in the results, a few of the subthemes were dependent on acceptance. Also, having an income to be able to provide for themselves or family, resulted in hope for some service users. This, in our opinion, also points to the layered, iterative and non-linear nature of the recovery process.

As was anticipated at the outset, the first five themes did correspond, in varying degrees, with the CHIME processes. What was also anticipated and ultimately found, is that

the specific applicability of some of the sub-components of the CHIME processes, where they correlated with the study's subthemes, and what they might mean for individual participants in this context might be different to other contexts in which the CHIME processes have been applied (Bird et al., 2014; Brijnath, 2015; Piat et al., 2017; Slade et al., 2012; Van Weeghel et al., 2019).

Limitations

The recruitment of participants was biased in that service provider contact persons identified the service users and some of the carers for participation in the study. This might mean that some of the service user or carer participants were selected by these persons to present a certain favourable view of their public mental health services. The first author tried, as far as was possible, to assure service user and carer participants of her independence of the mental health services of which the service provider contact persons were part. We were also reliant on the service provider contact persons to provide some names of potential carer participants, since the service users who participated were not always able to provide a reference to carers.

The fact that the interviews and focus groups were conducted by the first author as part of a larger study meant that time and resources were limited to extend the participant sample. However, data saturation was reached through the interviews that were conducted.

Recommendations

The data from this study came from a small sample of potential participants in the Western Cape province of South Africa. Replication of this study with larger groups of participants and in other settings in South Africa is recommended to determine whether the same results are obtained in various settings and to possibly strengthen the generalisability of the results.

The inclusion of service users' perspective as experts by experience in this study is to emphasise the crucial importance of their voices in understanding mental health recovery. Future studies should do the same. (Kleintjes et al., 2013)

This study's focus was on recovery within the individual, but future research into recovery-conducive environments in the South Africa public mental health sector is also needed, as in other, international settings (Rogers 2019), to ultimately complement personal recovery for service users through development of sufficient support by services (Kleintjes et al., 2012; Parker, 2012; Parker, 2014).

Conclusion

The data from this study that allowed for the use of the CHIME recovery processes (Leamy et al., 2011) and expansion by the addition of themes specifically related to the South African context, provides further evidence for the universality of certain recovery processes, yet the necessity of staying aware of local context differences (Van Weeghel et al., 2019). From the themes, a definition of recovery for the South African context was developed. The resultant definition of recovery is that recovery in the South African context is regarded as:

> An on-going, gradual, iterative and long-term process for service users (in collaboration with service providers and carers), after being in an acute mental illness state, which may include one or more themes such as relating to self, others, or the world, moving positively forward, (re-)gaining strengths, awareness of difficulties and a clinical understanding to support personal recovery.

This study is one of the first of its kind to explore the understanding of recovery from the perspective of service users, service providers and carers in the South African context. The results and definition are being used to inform the second phase of the overall study, which is to develop a measure of personal mental health recovery for the South African context. Measurement of individual recovery is not only helpful for the service user in

understanding their own process of recovery better with service providers and carers and to be able to move along in that process, but it can also be helpful in contributing to the wider clinical, academic and governmental comprehension of the process of recovery, be useful in determining the impact of recovery-oriented programmes and guiding decisions on continued funding of such initiatives.

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Chapter 5: Manuscript 2

5.1. Title

From darkness to light: Barriers and facilitators to mental health recovery in the South African context

5.2. Authors

Anneliese de Wet and Chrisma Pretorius

5.3. Focus of the article

In this research article, we report on the findings relating to the barriers and facilitators to mental health recovery, emanating from the interviews and focus group discussions with service users, carers and service providers in the study. We used reflexive thematic analysis to analyse the qualitative data and generated five themes each for the barriers and facilitators. The five themes for barriers to recovery were: 1) environment, 2) family, 3) public mental health services, 4) stigma, and 5) service users' attitude or behaviour. The five themes for facilitators of recovery were: 1) support, 2) family or friends, 3) service providers, 4) structure and, 5) empowerment. An underlying component to all the themes was the need for support. We also discuss the context of the study that provides an understanding for these barriers and facilitators and recommend directions for future research. (De Wet & Pretorius, 2020a).

5.4. Contribution to aims of the dissertation

This manuscript contributes to the dissertation aims by reporting on those influences in a service user's life which contribute to them being able, or not being able to participate in their own recovery. These findings contribute to informing the recovery definition and the items as part of the development of a measure of individual recovery for service users in the study context.

5.5. Publication status

As at 21 January 2021, the article, *From darkness to light: Barriers and facilitators to mental health recovery in the South African context* was published in the *International Journal of Social Psychiatry*.

5.6. Article

Please note: This manuscript is included in the format that it was submitted to the journal. Reference styles, format and layout are according to the specifications stipulated by the journal and do not necessarily conform to the style used in the dissertation.

From darkness to light: Barriers and facilitators to mental health recovery in the South African context

Anneliese de Wet and Chrisma Pretorius

Psychology Department, Stellenbosch University

Author note

Anneliese de Wet ORCID iD 0000-0002-8121-8698

Chrisma Pretorius ORCID iD 0000-0002-9188-0255

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Correspondence concerning this article should be addressed to Anneliese de Wet, Department of Psychology, Stellenbosch University, Private Bag X1, Matieland, 7602, South Africa. Email: anneliesedewet@sun.ac.za

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Abstract

Background: South Africa is a low and middle income country facing many challenges in public mental health care and implementation of recovery. ***Aims:*** To contribute to what barriers and facilitators to recovery might be for service users in South Africa, from the perspective of service users, carers and service providers from three psychiatric hospitals in the Western Cape province. ***Method***: Thirty-seven interviews and 3 focus groups were conducted with service users, carers and service providers. Interviews and focus groups were transcribed and analysed using atlas.ti software and reflexive thematic analysis, from the bottom up. ***Results***: The barriers, *environment*, *family*, *public mental health services*, *stigma* and *service users' attitude or behaviour* generated, were found to be the most salient. The facilitators to recovery generated were *support*, *family or friends*, *service providers*, *structure* and *empowerment*. The need for support was identified as an underlying component to all these themes. ***Conclusion***: Barriers and facilitators to recovery seemed to have both intrapersonal and external sources that intersect at times. Recovery needs to be supported at an individual level, especially through an under-utilised resource such as peer support work, but in conjunction with the development of recovery-enabling environments in services and communities in South Africa. (200 words)

Keywords: barriers, facilitators, mental health recovery, South Africa, qualitative; peer support work

From darkness to light: Barriers and facilitators to mental health recovery in the South African context

"It [peer support groups] tend to give us hope that there's a light at the end of the tunnel. No matter where you come from, what kind of obstacles that you have met in your path to where you are now, you can find your way out of that."

(Male service user)

The reference by a participant to light can be regarded as a metaphor for what could act as a barrier (darkness) to and what facilitates (light) recovery.

The focus of the larger study, from which the data reported on here originate, is the development of a measure of individual recovery for public mental health service users (SUs) in South Africa. It is one of the first such studies in South Africa. Data on the understanding of recovery and the development of the recovery measure were reported on elsewhere and consequently we formulated the definition of recovery for the South African context as,

> An on-going, gradual, iterative and long-term process for SUs (in collaboration with service providers (SPs) and carers), after being in an acute mental illness state, which may include one or more themes such as relating to self, others, or the world, moving positively forward, (re-)gaining strengths, awareness of difficulties and a clinical understanding to support personal recovery.

We mapped the first five themes of this definition onto the recovery processes, called the CHIME framework, of Leamy et al. (2011), but we found the last two themes, awareness of difficulties and a clinical understanding to support personal recovery, to be distinct from the CHIME framework (Leamy et al., 2011). The theme, awareness of difficulties, comprised barriers, on which participants elaborated. Participants also discussed facilitators to recovery.

South Africa is a low and middle income country, facing challenges, such as poverty, limited resources, inequality, obstacles in access to mental healthcare as well as failure by

government to prioritise mental health care (De Wet et al., 2019; Kleintjes et al., 2013; Lund et al., 2012; Lund, 2018) and a struggle for social cohesion, which influence the barriers and facilitators to recovery for SUs. In particular, South Africa's public mental health services are not prioritised in health care budgets and are still delivered mostly on an institutional basis, through tertiary psychiatric hospitals (Docrat et al., 2019; De Wet et al., 2019). Within public mental health services, only very few programmes, that are specifically based on recovery principles, exist yet (De Wet et al., 2019). This, despite recovery having been mandated in the National Mental Health Policy Framework and Strategic Plan 2013-2020 (South African Department of Health, 2013). Added to the limited financial resources allocated to and limited amount of health care staff in public mental health services, it creates an environment in which many SPs want to, but are often unable to provide SUs with the care required to support them fully in their recovery (Jacob, 2015; Kleintjes et al., 2013; Lund et al., 2012; Parker, 2012; Stein, 2014; Sunkel, 2014). SUs are often discharged before they are ready, to make place for other or more acutely ill SUs and this leads to repeated re-admissions (Docrat et al., 2019).

In this article, we discuss some barriers and facilitators to recovery for SUs, from our study, given the general and mental health care context in South Africa.

Method

Participants

Data were collected in 2018 and 2019 by conducting interviews with 1) SUs, who could speak English or Afrikaans (a local language), with a severe or chronic psychosocial disability and had cumulatively, over their mental health treatment history, spent 6 or more months at a tertiary public psychiatric hospital in the Western Cape province of South Africa and participated in some mental health programme at the hospital, 2) their SPs and 3) their carers (relatives). The first author conducted all 37 interviews. Thirteen interviews were with

SUs, 12 with carers (all relatives of SUs who met inclusion criteria) and 12 SPs. The first author held three validating focus groups, one with each cohort of participants, i.e. one with four SUs, one with three SPs and one with three carers. In Table 1 we provide participant descriptions and inclusion criteria.

Table 1

Participant Descriptions and Inclusion Criteria

Participant Cohort (n = 38[a])	Diagnosis (SUs)	Inclusion Criteria
Female: n = 22 Male: n = 16	Relationship to SU (Carers) Occupation (SPs)	
SUs (n = 14) Female: n = 4 Male: n = 10 Ages: between 23 and 47 years	Bipolar mood disorder (n = 3) Schizoaffective disorder (n = 2) Schizophrenia (n = 9)	- English/Afrikaans speaking - Severe / chronic psychosocial disability - 6+ months as in-patient in hospital - Participated in programme/intervention at hospital
Carers (n = 12) Female: n = 10 Male: n = 2	Mothers (n = 5) Brother (n = 1) Sisters (n = 2) Son (n = 1)	Family members or others involved in the financial or emotional support of and caring for SUs

	Daughter (n = 1) Aunt (n = 1) Niece (n = 1)	
SPs (n = 12) Female: n = 8 Male: n = 4	Social worker (n = 1) Nurses (n = 3) Psychiatrists (n = 2) Occupational therapists (n = 2) Occupational therapy technician (n = 1) Psychologists (n = 3)	Directly / indirectly involved in the provision of services / interventions / programmes to the SU participants

Note. [a]Although only 37 persons participated in the interviews, there were 38 participants overall. One additional SU was included in the focus group discussions, due to one of the original interview participants declining to take part in the follow-up focus group.

Procedures

We obtained ethical approval from Stellenbosch University's Research Ethics Committee: Human Research (Humanities) (Reference number PSY-2017-1711) and the Western Cape Provincial Department of Health (Reference number WC_201801_032). Recruitment took place through the Department of Health, who appointed contact persons at the three hospitals. We were not allowed to approach SUs directly, so SPs, to whom the duty to assist us had been delegated, assisted in identifying and introducing us to SUs who met inclusion criteria. We approached SPs at the hospitals for interviews. Carers were identified

either by SUs or SPs. The study was explained to all participants, who could ask questions, decline participation and signed an informed consent form of which a copy was offered to them. Participants were assured of confidentiality of their identities. The interviews were audio-recorded with participants' consent. Interviews were conducted, depending on the participant's preference, in English or Afrikaans, with the latter being the most widely spoken home language in the Western Cape (Statistics South Africa, 2011).

The interviews and focus groups were in-depth and semi-structured, using an interview schedule and focus group interview guide, and explored participants' understanding of recovery (reported on elsewhere) as well as what hinders and what helps recovery. The interviews lasted between 33 and 87 minutes and focus groups between 52 and 93 minutes. Data saturation was reached.

Data analysis

Interviews were transcribed and quality checked. We used atlas.ti data analysis software (Atlas.ti, Version 8.4.4) together with reflexive thematic analysis (Braun & Clarke, 2006, 2019) to analyse the data, bottom up. The first author created quotations, annotated quotations, coded quotations and then generated themes of barriers and facilitators. The authors discussed the quotations, codes and themes with each other throughout analysis to ensure trustworthiness and refine the results. The first author checked the themes against the transcriptions to ensure that the themes related well to the original data.

Results and discussion

The theme, awareness of difficulties, from our definition of recovery in South Africa, comprised barriers. Participants discussed these barriers, including setbacks, loss as well as the intermittent and iterative nature of the recovery process, which could also prove to be challenging. Participants' awareness of these barriers was to be expected in a demanding socio-economic context such as South Africa where the majority of the population, reliant on

public mental health services, encounter obstacles and limited resources, not only in their communities but also in receiving mental health care (De Wet et al., 2019), which may influence their mental health negatively (Schneider et al., 2016).

We elaborate on these barriers and explore facilitators to recovery, that were identified by study participants.

Barriers

Participants discussed many barriers, of which *environment*, *family*, *public mental health services*, *stigma* and *SUs' attitude or behaviour* were most salient. The two barriers mentioned the most by far were *environment* and *family*.

Environment. A recovery non-conducive environment was identified both at the hospital and in communities. We discuss the community environment here. The hospital environment will be discussed under *public mental health services.* It is not surprising that the environment was mentioned frequently, given the nature of the study context described earlier. On a basic level, barriers such as lack of food and accommodation, because of a lack of work and resulting income, as well as a lack of refuge, were cited. One male SU said, "So I have no symptoms now and I have no place to stay." This quote is illustrative of many other participants' statements, that families often do not accommodate SUs upon discharge, leaving the SUs in institutional care, because SPs cannot discharge them without refuge in the community. Poor social conditions, with "lack of … supportive structures in community…", indicated by a female occupational therapist, and over-crowding, that are often characteristic of impoverished communities of origin of most SUs in this study, were additionally cited as factors detracting from recovery. In their communities, many SUs were further challenged by substances, especially methamphetamine, being easily available and thus tempted into using these substances upon discharge. Substance use has been linked to the revolving door

phenomenon (Petersen & Lund, 2011) and mental illness (Jacob & Coetzee, 2018) being very prevalent in the context.

These environmental factors exacerbate the general challenges of mental health conditions and thus affect SUs' recovery adversely (Kleintjes et al., 2012).

Family. Participants reported feeling isolated, partly because of an absence of contact or communication with family when in hospital, whether because of stigma, financial constraints or other reasons, that prohibit family from visiting. One female social worker said that SUs often confided in her, "I think my family don't love me.", in response to families' lack of involvement or visits.

Expectations of SUs also added to pressure and judgement SUs experienced in the family context. A female SU expressed this by relating what her aunt said, "…everything depends on me [SU] to become healthy, for my children's sakes." These expectations might be due to the lack of knowledge about mental illness and recovery by family members, who often expect SUs to not experience any symptoms upon discharge.

Upon discharge, SUs, however, also felt they were questioned or watched by family and not trusted. A male SU said, "So that thing doesn't work in terms of recovery, you know, they watch each and every movement that you're doing at home…"

Family, even though it should be a refuge of acceptance and support (Kleintjes et al., 2012), was often cited as an obstacle for recovery.

Public mental health services. Especially SPs, confessed that SUs often had to be discharged to make space for others SUs awaiting treatment. A female psychologist acknowledged their limited resources created an environment where almost only those SUs struggling with severe symptoms receive attention, "You almost like have to earn your place…" Too early discharge has been described as a cause of regular re-admission of SUs in this context (Docrat & Lund, 2019, October 9; Petersen & Lund, 2011).

SPs also recognised that high turnover in staff created challenges for SUs, who wished for SPs to remain in their positions. One male psychologist expressed SUs' dismay as, "You're [SP] not going to leave us [SU] again."

Participants also emphasised SUs' lack of agency while in hospital; being told what to do and when to do it. A male SU described it practically as, "Even the TV time, like 5pm they lock us in and then you're going to be able to watch TV at 8pm." This lack of decision-making power can lead to institutionalisation for SUs. In a country, such as South Africa, where public mental health services are still delivered largely on an institutional basis, with resource-constraints, uniform treatment of SUs and given the social context that requires some SUs to stay in tertiary mental health care longer than necessary, institutionalisation is prevalent and, in turn, not only aggravates the lack of agency, but can result in dependence, helplessness and (self-)stigmatisation. A female psychologist summarised it, "…the longer they're here, the more they perceive themselves as this crazy person. That's all they are. That's all they can ever be."

These factors, together with the lack of sufficient support from government for mental health services (Petersen & Lund, 2011) and resultant pressure on such services (Lund et al., 2012), contribute to a public mental health service which does not support recovery adequately. Mental health services need to be strengthened on every level (Jacob & Coetzee, 2018).

Stigma. "Like, nobody's got faith in me. Or I'm like a demon…" was one male SU's highly stigmatised perception of himself. Institutionalisation was also closely linked to stigma in the study. A female carer (sister of a SU) expressed it plainly as, "…we didn't want to have her institutionalised. A lot of stigma goes with that."

Other general challenges that most South Africans faced, like getting work, was even greater for SUs, because of stigma. A male SU explained, "Some other jobs I don't think they

can accommodate people that have disability, not unless that company is willing to do that." Another male SU elaborated on the effects of stigma,

> They heard you've got mental illness and it's a sickness for life. And then that's where they have doubts about you being friendly, or being communicative or, landing up lending something or borrowing you something and they're like distancing themselves from you. And your life suddenly changes. It's like you're blindfolded. There's nobody you can count on, then the hopeless starts taking place and you feel like a nobody. That's what I experience.

Stigma ultimately leads to feelings of hopelessness and insignificance (Kleintjes et al., 2012), which can counter the recovery gains that may have been made by SUs.

SUs' attitude or behaviour. Some participants regarded SUs' attitude or behaviour as standing in the way of their own recovery, at times. Although identified as a barrier, it is necessary to emphasise that it does not exist in isolation, but is also influenced by social, environmental or institutional factors on the SU, some already mentioned. Examples of such attitudes or behaviour are aggression, lack of self-care, negativity, lack of trust of others, lack of awareness and lack of responsibility. A male psychologist regarded "…a negative attitude … towards the recovery process" in the first instance as a barrier. One male SU expressed responsibility required as, "...patient must work [on] himself for a recovery." Prioritisation of mental health resources by health departments and the fostering of further and more, sincere collaboration between SPs, carers and SUs could adjust the attitudes or behaviours of SUs to support recovery.

Peer support work (PSW) is the facilitation of a SU's recovery process through the assistance by other SUs (Puschner, 2018). PSW has been validated through research, however, it is still an under-utilised resource in South Africa (Vally & Abrahams, 2016). Implementing PSW can potentially play a role to mitigate the identified barriers to recovery,

by counteracting the lack of supportive structures in communities, reduce re-admissions and help address stigma and SUs' attitudes or behaviour.

Facilitators

Participants emphasised many facilitators in their recovery too. The most salient of these were *support*, *family or friends*, *SPs*, *structure* and *empowerment*.

Support. The biggest identified facilitator of recovery was support of SUs by family, friends and SPs. Support encompassed care for, genuine interest in, compassion for, belief in, encouragement or motivation of, and non-judgement of SUs. Many participants echoed this succinct sentiment of a male nurse, "Recovery is support." A female occupational therapist emphasised the positive influence of family participation, "…the more family we have involved, or family support we have, the better."

Participants mentioned that spirituality, such as attending church, praying and faith or belief in a higher power, also supported SUs by providing hope, meaning, acceptance and motivation to overcome isolation and negativity. "So, it [believing] helps me in a sense that make me want to think positive and not in a negative way", said a male SU. A carer sister described her brother's faith, "That [faith] has also been a support in his life…" and confirming that "It [faith] does plays a role in his recovery…" A psychiatrist was convinced that, "…if people believe in something, they have a better chance."

Support can contribute to a healthy, stable environment for SUs in which they could be recovering safely and securely (Kleintjes et al., 2012).

Family or friends. An important facilitator of recovery was family and friends. Participants referred to them positively using words such as "honesty" in terms of relationships between SUs and friends or family, "knowledge" in terms of carers being vigilant for relapses, "role model" of a friend or family member, "connection" between SU and friends or family,

"support" of friends or family, and "trust". A female occupational therapist stated that, "…family's an asset to recovery…"

When asked what supports him to not give up on his recovery, a male SU said, "My friends and my sister. For them, when they are giving words that they trust me. When they show that they trust me. I tend to have that courage." Just further along in the same interview, he also referred to the trust he has in others, "having someone to talk to that you [SU] trust" and that it is accompanied by trusted others being honest with him.

Receiving, but also giving support to friends was important for a male SU as he was "…building a team, my team."

Connection for SUs was regarded as one of the important aspects of recovery by a female occupational therapist, "Re-connection to self, re-connection to on, on, on many levels…" Knowledge of illness by families was also cited as supportive to SUs being prepared for relapses.

Service providers. The attitude of SPs towards SUs was regarded as crucial to recovery. A male psychologist explained the need for SPs acknowledging their common humanity with SUs, "They [SUs] are human, ja. Umm… We [SPs] are human. Umm… and I think that, that's what make the difference. Cause that's how we [SPs and SUs] need to relate to each other." This humane approach (Farkas, 2007) is an echo of South African studies that have advocated for it before (Kleintjes et al., 2012).

Some hospital interventions that specific SPs facilitated, like a market garden project and sharing life stories amongst SUs, both recovery-based, seemed to have anecdotal beneficial effects on the recovery of SUs. SUs received a stipend for their work in the market garden and, "...immediately it raises...your [SU's] position in the...household", confirmed a female occupational therapy technician. She also speculated on how acquisition of skills in the market garden project could make SUs feel, "And it [acquired skills] makes you feel in

terms of the mental illness that you have, you can live with it, because you can also do something." According to the female occupational therapist involved, sharing life stories amongst SUs "…can be the basis for the rest of their recovery process."

Except for the role that family and friends and SPs play separately, the collaboration between SPs and family, which is necessary to facilitate recovery, was also emphasised by participants and is indeed necessary (Kleintjes et al., 2012).

Structure. Structure included routine and order to support SUs in their recovery. One male SU was adamant that routine and structure was essential to his recovery, "Doing like a timetable or a roster for myself what I'm going to do during the week. Like going to drumming or wake up and exercise, drumming, going to library, printing my stuff, my CV and handing [CV] over..." A female SU felt getting up at a certain time every morning assisted her, "…every day I get up at more or less the same time" as well as "…do[ing] more or less the same thing every day." These excerpts emphasise the predictability that exists in routine and structure for SUs, helping them in their recovery. This female SU's carer, in a later interview, re-iterated routine giving a sense of control to the female SU. One female psychiatrist linked routine with responsibility and that, in turn, giving a SU purpose and building self-esteem.

Structure can provide the scaffolding necessary for the recovery process of the SU.

Empowerment. Referring to empowerment, participants emphasised the need for some independence or sense of agency for SUs in their recovery. One male carer expressed it as, "So, that independence I think is also important for his recovery." A female psychologist highlighted the empowering role the multidisciplinary team can have in encouraging SUs to voice their needs, "…a part of the multi-disciplinary team's work is very much empowering them to be able to voice, to give them a voice."

A male psychologist referred to the empowerment of SUs that comes from sharing experiences with other SUs, "When they come back [SUs from a leave of absence from hospital] and we're in a group, a group setting sometimes you [returning SU] perhaps want to share what your experience has been like. And, in that way they [rest of the group] can also perhaps somehow feel empowered." This indicates the empowerment potential of PSW (Lund et al., 2012), which needs further development in South Africa and could be a powerful resource given the great financial and resource constraints faced in the country.

Except for SUs own attitudes or behaviours, which were influenced by environmental factors, the barriers to recovery seemed to stem, to a large extent, from external sources related to interpersonal (family), community, institutional, and societal factors, which also intersect. The recovery-promoting facilitators seemed to centre not only around relational factors, predominantly in the form of support, but also around systemic factors through empowerment and structure. It is our opinion that recovery is facilitated where SUs are aided to develop their own strength to recover, but importantly, in conjunction with enabling environmental factors (Kleintjes et al., 2013). Public mental health departments and services need to look at investing in recovery-enabling environments within services, that are oriented towards the SU to involve them in their recovery meaningfully (Farkas, 2007), and develop formal PSW, the latter which can collaborate with community organisations to also work towards more recovery-enabling environments within communities through which other barriers, such as stigma, can be addressed too.

Limitations

The small number of participants limits generalisability. However, it is not the aim of qualitative research to be generalisable or representative, but rather to provide a rich description of the participants' experiences, until saturation is reached. We achieved this as well as through triangulation of results by including three cohorts of participants. In so far as

the results can potentially be representative, they may however not be representative of other parts of South Africa. The public mental health spend per capita in the Western Cape is the highest in South Africa. In other provinces, this spend has ranged from only 19% up to 82% of the amount spent in the Western Cape (Docrat et al., 2019). This may also have an influence on the experiences of similar potential participants in other provinces.

Recommendations

Since this was a small-scale study and barriers and facilitators might differ for SUs in other contexts, it is recommended that the study be replicated in other provinces in South Africa to determine whether results are similar for such participants to those found in this study. It is also recommended that the further development of PSW be investigated as an additional resource for SUs in their recovery process.

Conclusion

The barriers and facilitators discussed seemed to link with each other and we found it difficult to discuss one without finding overlap with another. This indicates how individual (SUs and SPs), social (family, friends and community), institutional (overall mental health services and government) and societal (social conditions) factors weave an intricate web of conditions and create intersections, which make the recovery process particularly complicated and challenging, especially for SUs in South Africa. However, the need for support seemed to cut across all these factors. In South Africa, a largely untapped, potential recovery resource, PSW, could be developed further with proper regulation of who delivers PSW, how PSW is delivered and evaluated (Vally & Abrahams, 2016) as well as appropriate training programmes for peer support workers (PSWs) in the context (Pathare, 2018). As the need for support was an underlying component to all the barrier and facilitator themes, PSW could address this underlying need very well. This could be by not only supporting SUs in their recovery, but also lending support to SPs and mental health services in relieving the

overwhelming burden of care that they carry, providing previous SUs (who become PSWs) with meaningful work and much-needed income, and addressing stigma due to more wide-spread knowledge of mental health in communities. Ultimately, PSW could also be financially beneficial to health departments (Moran et al., 2020) and, overall, provide hope through some light at the end of the recovery tunnel.

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Chapter 6: Manuscript 3

6.1. Title

Development and Content Validity of a Preliminary Version of the Measure of Individual Mental Health Recovery for the South African Context

6.2. Authors

Anneliese de Wet and Chrisma Pretorius

6.3. Focus of the article

In this methodological research article, we report on the development of a recovery measure and the testing of content validity of a preliminary version of a recovery measure for the study context. We used the definition and dimensions of recovery as well as the barriers to, and facilitators of, recovery, from a previous part of the study, together with a literature review of international recovery measures, to develop items and draft the format of the measure. We then tested the content validity of this preliminary version of the measure by using a Delphi panel of professional experts, cognitive interviews with experts by experience, matching of items and dimensions by professional experts and a readability test. We also discuss challenges encountered in the process of development in the context of the study and recommendations when embarking on such a process.

6.4. Contribution to aims of the dissertation

This manuscript contributes to the dissertation aims by reporting on the process of development of the recovery measure and testing for content validity. These findings conclude the study by accomplishing the overall goal of the study, which is to develop a contextually appropriate measure of individual recovery for mental health service users in the South African context.

6.5. Publication status

As at 21 January 2021, the article, *Development and content validity of a preliminary version of the Measure of Individual Mental Health Recovery for the South African Context* was submitted for publication in, and under review at, *Psychiatry Research*.

6.6. Article

Please note: This manuscript is included in the format that it was submitted to the journal. Reference styles, format and layout are according to the specifications stipulated by the journal and do not necessarily conform to the style used in the dissertation.

Development and content validity of a preliminary version of the Measure of Individual Mental Health Recovery for the South African context

Anneliese de Wet[1], Chrisma Pretorius

Psychology Department, Stellenbosch University, Stellenbosch, Western Cape province, South Africa

Word count (exclusive of tables, figures, and references): 4 828 words

[1] Corresponding author at: Psychology Department, Stellenbosch University, Private Bag X1, Matieland, 7602, South Africa.
E-mail address: anneliese.dewet@gmail.com (A. de Wet).

Abstract

The aim was to develop a mental health recovery measure and test content validity, since an abundance of mental health recovery measures exists in high-income countries, yet no such measure has been developed for the South African context, which differs considerably. The definition and dimensions of recovery, developed in a previous part of the study, was expounded, used to formulate items and decide on the format of the measure. These items were tested for content validity through a 2-round Delphi panel of professional experts, cognitive interviews with four service users, the matching of items and dimensions by clinical experts, over two rounds, and a readability test. The initial measure consisted of 63 items, reduced to 48 through the Delphi panel and then to 39 through the recommendations by a psychometry expert and then finally to 38 items after cognitive interviews with service users and matching of items and dimensions by clinical experts. Recovery measure development is necessary for South Africa, where no such measure exists. Challenges encountered in the process are a protracted process and unanticipated considerations regarding ethics and the participants in the study. Researchers should ensure that they are sufficiently prepared for the process and the study context. (200 words)

Keywords: Recovery; Mental Illness; People in recovery of mental illness; Service users; Mental health service providers; South Africa; Methodology

Highlights

- In-depth discussion of the methodological aspects of mental health recovery measure development
- Identifying some challenges that might be encountered in measure development
- Despite a multitude of literature on general psychological scale development, very few discussions on the practical process and challenges of specific scale development are available

1. Introduction

In the international field of mental health recovery, specifically in high-income countries, an abundance of individual recovery measures has been developed. This is evidenced by systematic as well as literature reviews to determine the quality of these individual measures (Shanks et al., 2013; Scheyett et al., 2013; Sklar et al., 2013). Yet, no such measure has been developed specifically for the South African context. The aim of this study was to develop a measure of individual recovery for service users in the South African context and do preliminary validity testing of such measure. A new recovery measure, as opposed to employing an existing international measure, was developed, because of the unique challenges that are faced and which could translate to unique meanings attributed to the recovery concept by service users in the South African setting. South Africa has a history of segregation and consequently a disproportionately small amount of and often severely inadequate, largely underdeveloped, and mostly institution-based public mental health resources are allocated to the majority of persons in its society (Jacob, 2015; Kleintjes et al., 2013; Lund et al., 2012; Parker, 2012; Stein, 2014; Sunkel, 2014). This history of South Africa, together with its consequences, created a backdrop against which the participants in the study setting were expected to have very different understandings of recovery-related concepts than service users in developed world settings where existing measures have their origin. The recovery understandings of service users, who are faced with low socio-economic status such as the participants in this study, are informed by the insecurities that they face and the (in-)ability of relevant government departments to sufficiently address the needs that arise from these insecurities.

Following on from the first part of this study (of which the results will be reported elsewhere), which entailed the qualitative exploration of the perceptions and understanding of recovery in the South African context (by service users, service providers and carers) and

resulting in a proposed definition of recovery, a measure for individual recovery for the South African context was developed. The focus of this article is on the methodological second part of the study, which involved the development of items, the process of reducing and refining such items, content validation processes as well as some challenges encountered in the process. This is to contribute to an understanding by researchers, embarking on a process of developing context-appropriate measurement instruments in the mental health field, of the challenges involved in such a process.

Figure 1 presents an overview of the study.

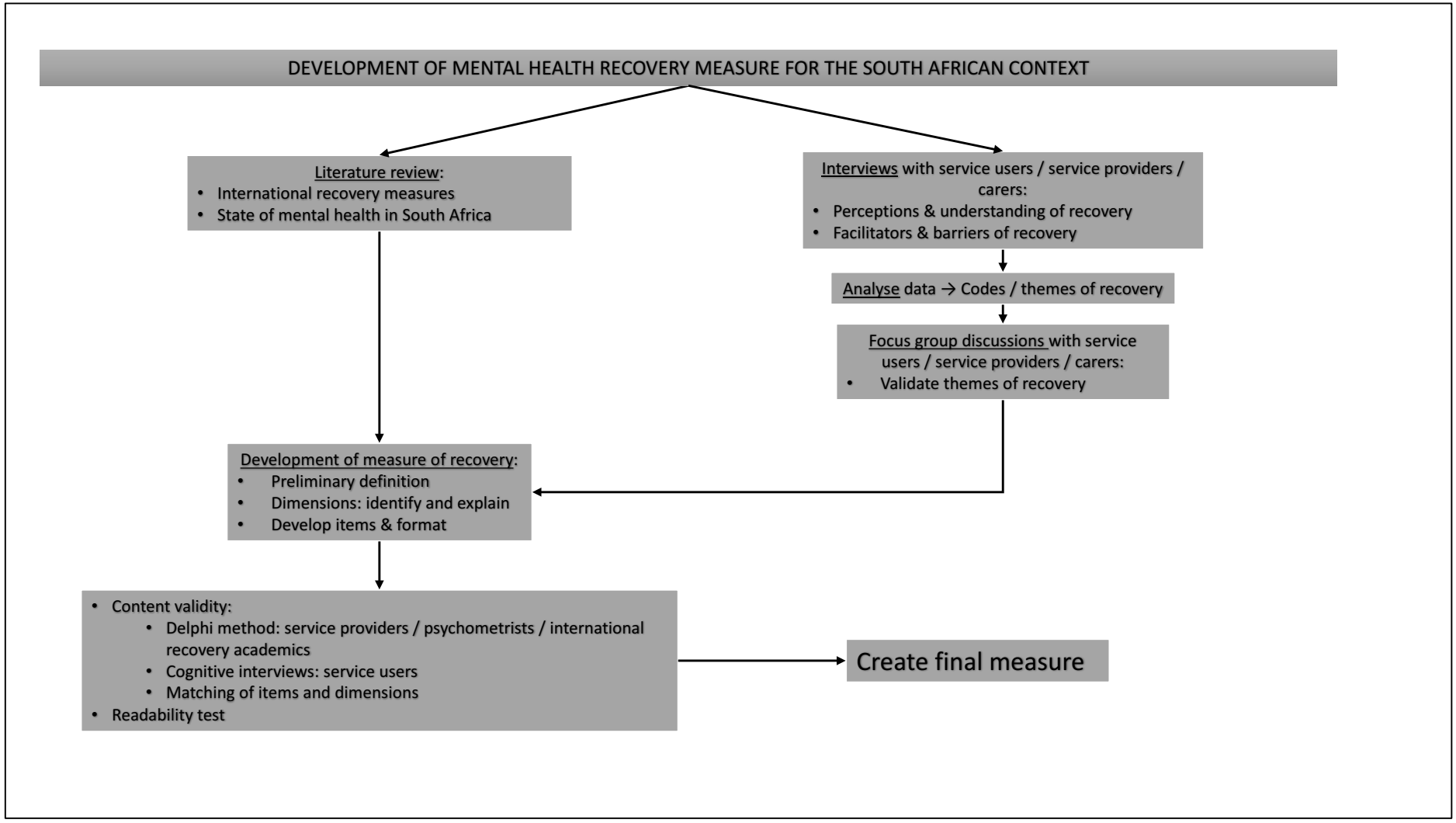

Fig. 1. Overview of the study.

The definition of recovery, that was developed, is that

> recovery in the South African context is regarded as an on-going, gradual, iterative and long-term process for service users (in collaboration with service providers and carers), after being in an acute mental illness state, which may include one or more themes such as relating to self, others, or the world, moving positively forward, (re-)gaining strengths, awareness of difficulties and a clinical understanding to support personal recovery.

This definition encompasses the seven broad themes (hereinafter referred to as dimensions) of recovery that were generated. Five of these dimensions are broadly related, in varying degrees, to the five recovery processes put forward as part of the well-known CHIME framework that followed from the systematic review and narrative synthesis of 97 studies on personal recovery that Leamy et al. conducted in 2011.

2. Methods

2.1. Participants

Data for the first and qualitative part of the study were gathered, through interviews and focus groups, from service users, with a severe or chronic psychosocial disability who had spent 6 or more months as an in-patient in a tertiary public psychiatric hospital in the Western Cape in South Africa and participated in some mental health programme at the hospital, their service providers as well as their carers (relatives). This second part of the study involved four service users (cognitive interviews) and seven service providers (two for the Delphi panel and five for matching of items and dimensions) from the same cohorts as the first part of the study, as well as two international academics with expertise in recovery and two South African experts in psychometry (the last two groups both for the Delphi panel). Consult Figure 2 to further understand where the participants fit into the various developmental steps.

2.2. Ethical considerations

Before the first and qualitative part of the study, ethical approval was obtained from Stellenbosch University's Research Ethics Committee: Human Research (Humanities) (Reference number PSY-2017-1711) and the Western Cape Provincial Department of Health (Reference number WC_201801_032), which approvals had to be obtained consecutively. After the initial version of the measure was developed and before the content validity process, ethical approval had to be sought again from both boards, before the measure could be presented to participants. This added additional time to the study duration.

2.3. Procedures

The broad steps in the development of the measure, after the definition had been formulated, consisted of, 1) expounding the dimensions of the recovery definition, 2) drafting the measure by formulating items and deciding on the format, 3) first part of content validity, being a Delphi panel, 4) second part of content validity, being cognitive interviews and matching of items and dimensions, and 5) a readability test and final check.

Figure 2 presents the steps in the development of the measure.

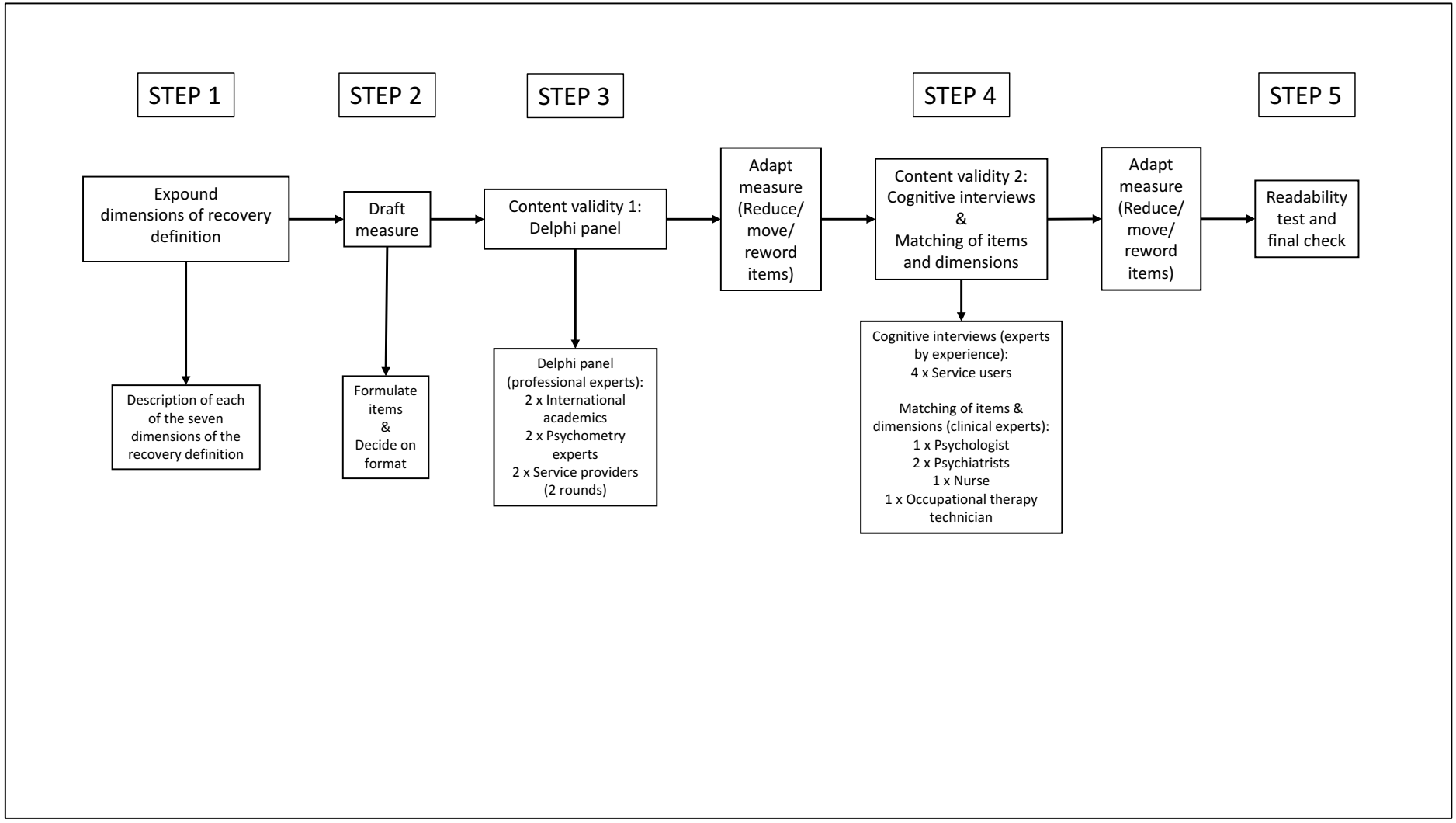

Fig. 2. Steps in the development of the measure.

3. Results

3.1. Expound dimensions of recovery definition

The first step in the development of the recovery measure, which was a continuation from the qualitative part of the study, was to expound each of the dimensions of the recovery definition. The seven dimensions generated were, 1) Relationships with others, 2) Moving positively forward, 3) Relationship with self, 4) Relating to the world 5) (Re-)gaining of strengths, 6) Awareness of difficulties, and 7) Clinical understanding to support personal recovery, with the first five being broadly related to the CHIME framework (Leamy et al., 2011), respectively, and the last two generated directly from the study data. Each dimension was considered, together with its sub-dimensions, also generated during the first part of the study, and a description of the dimension, which encompassed its sub-dimensions, was formulated to expound such dimension and give a more general description of each dimension's significance for service users. The dimensions, their sub-dimensions and general descriptions can be found in Table 1 and formed a basis from which the measurement items could be formulated and checked during the refining process to ensure that the items, formulated as part of certain dimensions, stayed within the parameters of their respective dimensions.

Table 1

Dimensions and sub-dimensions, of recovery definition, and their general descriptions

	Dimension	**Sub-dimension**	**General description of dimension**
Dimension 1	Relationships with others	Connection and Support	The importance of relationships with others for service users in their recovery process.
Dimension 2	Moving positively forward	Adapt and Hope	The wish of service users to move positively forward with their lives and to envision a future for themselves with their mental illness.
Dimension 3	Relationship with self	Identity, Routine and Renewal	The service users' relationships with themselves and (re-) building those relationships.
Dimension 4	Relating to the world	Meaning, Faith, Contribution and Insight	The need in service users' recovery process to also relate to, or make sense of their experiences in the world around them.
Dimension 5	(Re-)gaining of strengths	Income, Independence, Trust, Agency and Capacity	Service users (re-) gaining strength to function in the world, despite their mental illness.
Dimension 6	Awareness of difficulties	Challenges and limitations	Difficulties faced by service users in the recovery process and their awareness thereof.
Dimension 7	Clinical understanding to support personal recovery	No sub-dimension/s	The importance of some clinical understanding by service users to support their personal recovery process.

3.2. Draft measure - formulate items and decide on format

The second step was to formulate items for the measure, according to the seven dimensions. This step also involved deciding on the format of the measure.

For this step, firstly, the original interview data, especially with service users, in the qualitative part of the study was revisited to identify words or phrases that service users used to describe their recovery perceptions and understanding, so that such wording could be incorporated in the items. This was in an attempt to generate, at least, some items that would sound familiar to service users and make the measure more understandable and relatable to them.

Secondly, we identified existing measures of recovery that were fairly robust, reliable and employed in various high-income countries (Shanks et al., 2013; Sklar et al., 2013) in an attempt to determine what acceptable measures of mental health recovery contained in terms of items and format, so we could, in turn, decide on the items and format for the measure that we were drafting. There is no generally preferred instrument to measure recovery and so, no gold standard instrument in the field of recovery (Sklar et al., 2013). We examined two systematic reviews on mental health recovery measures, one from the United Kingdom (UK) by Shanks et al. (2013) and one from the United States of America (USA) by Sklar et al. (2013). The four measures that we identified in the process and used were 1) the Recovery Assessment Scale (RAS) by Giffort et al. (as cited in Corrigan et al., 2004), 2) the Questionnaire about the Process of Recovery (QPR) by Neil et al. (2009), 3) Maryland Assessment of people in Recovery with Serious mental illness (MARS) by Drapalski et al. (2012) and the 4) Recovery Assessment Scale – Domains and Stages (RAS-DS) by Hancock et al. (2015). Recovery (2015). The first three of these four measures were regarded highly in terms of their psychometric properties in the UK systematic review of thirteen personal recovery measures (Shanks et al., 2013). In the USA systematic review of thirteen mental

health recovery measures, the Recovery Assessment Scale (RAS) by Giffort et al. (1995; as cited in Corrigan et al., 2004) and the Maryland Assessment of people in Recovery with Serious mental illness (MARS) by Drapalski et al. (2012) were found to be psychometrically robust (Sklar et al., 2013). The fourth measure, the Recovery Assessment Scale – Domains and Stages (RAS-DS) (Hancock et al., 2015) was not yet available at the time of the systematic reviews by either Shanks et al. (2013) or Sklar et al. (2013), but was included after the first author was introduced to it by its developer at a conference and read about the instrument and its robustness subsequently (Hancock et al., 2015). We scrutinised their items as well as their format, instructions, length and response options and compared them to the dimensions in our study and our plans for drafting our initial measure.

We consulted the existing measures and the words and phrases from our qualitative data to develop items for and an initial format of the measure. We grouped the items according to the dimensions of recovery we generated. For the first version of the measure sixty-three items were formulated, some items were similarly-worded and items were in the first person as far as possible. We attempted to use plain English, as far as possible, for the instructions, to make them clear and unambiguous. A 5-point Likert scale for the response options was included. (In the supplemental material the items of the first version can be viewed in a table format compared to the four subsequent versions.) (For reviewers: see the table provided.)

Thirdly, the first author, who conceptualised the first version of the measure, presented it to and discussed the measure and its items with the second author and a South African academic expert in psychometry to advise on it in order to improve it. After these consultations, a conclusion was reached that a few issues existed regarding the abstractness and wording of some of the items in the measure. Through this feedback, the first author realised the challenge as a researcher to formulate items, that tap into a fairly abstract concept

such as recovery, and at the same time ensure that these items are clear, concise, unambiguous and concrete for a broad range of potential respondents (Spector, 1992). The psychometry expert also advised on some psychometric issues to be considered when testing the measure in future. Although this advice was not used in this study, it was noted for possible future testing. It was decided to retain the initial items, as they were at this stage, and note the issues raised regarding abstractness and wording for consideration at the end of the next step in the development process. We also relied on the very helpful, practical advice on scale development and validation in Boateng et al. (2018). The textbooks on scale development, procedures and construction by DeVellis (2017), Foxcroft and Roodt (2009), Netemeyer et al. (2003) and Spector (1992) were consulted to ensure that due consideration was given to a wide range of aspects of measure development. The content and format of the measure was now ready to be scrutinised further through various content validity processes.

3.3. Content validity: part 1 - Delphi expert consensus method

The third step of development was also the first step in content validity testing. The purpose of content validity is to determine whether the measure will perform what it was constructed to perform (Durrheim and Painter, 2010), in this case to measure individual mental health recovery, through testing of content relevance, representativeness and technical quality. Before this step could be proceeded with, ethical approval from both the university's research ethics committee and the provincial department of health was required for the preliminary measure. This process added more time to the study duration than what the researchers had initially planned.

Firstly, the Delphi expert consensus method (Jorm, 2015) was used in this step. The Delphi method was developed in the 1950s in the military field to obtain consensus amongst a group of experts on a particular topic (Landeta, 2006). Since then it has gained widespread use and more recently it has also been used in the mental health field to determine, among a

group of experts, the meaning of recovery (Law and Morrison, 2014), first aid recommendations for psychosis (Langlands et al., 2008) and symptoms of geriatric depression to inform the development of a scale (Xie et al., 2013, as cited in Xie et al., 2015).

Two rounds of the Delphi panel were held. In the first round, we employed a panel of six persons, consisting of two international academic experts in recovery and two South African experts in psychometry (other than the expert involved in the drafting of the measure step before) as well as two local clinical experts, who worked with the study population daily. The panellists were requested to advise on the adequacy of the measure to assess recovery by reviewing the representativeness of items in relation to the definition of recovery for the study context (Durrheim and Painter, 2010) as well as the appropriateness of the format and structure of the measure for mental health recovery and the technical quality of the measure (Boateng et al., 2018). This process took place by separate emails to each panel member to ensure the anonymity of panellists' identity to each other and so that each panellist was free to decide and comment without the influences that come with having to do so in a group of experts (Jorm, 2015). In between the two rounds feedback was given to panellists individually of the full results of the first round, without reference to the names of other panellists, to facilitate further development towards a final, consensus (Bloor and Wood, 2006; Landeta, 2006; Rowe et al., 1991). In the second round of the Delphi panel one of the South African experts in psychometry could not take part and we had to continue with five panellists in the second round. Over the two rounds, the items and format of the measure were considered, refined and some items eliminated.

Two dilemmas presented themselves during the analysis of the results from the Delphi panel. The first was an item that was to be included, according to the overall Delphi panel, but identified by one panellist as potentially negative and tapping into suicidal tendencies. This item was formulated as; *I feel like I can go on.* The dilemma was, if a

respondent were to answer no, it might bring up negative thought patterns, even suicidal thoughts, and break down possible gains that the respondent had made in their recovery journey. Considering our ethical duty as researchers to minimise harm to our potential respondents, who could be potentially particularly vulnerable, we decided to exclude this item from the measure. The other dilemma was an item that was to be excluded, according to the Delphi panel, yet having been emphasised by many interview and focus group participants as an important part of the recovery process. This item was, *Earning an income is important to me.* We consulted the qualitative data again in making a final decision on whether to include this item. Based on the support for the item in the qualitative data, we decided to include this item in the measure for the next step and thereafter make a final decision on the item.

Figure 3 illustrates how items were included or excluded through the rounds of the Delphi panel.

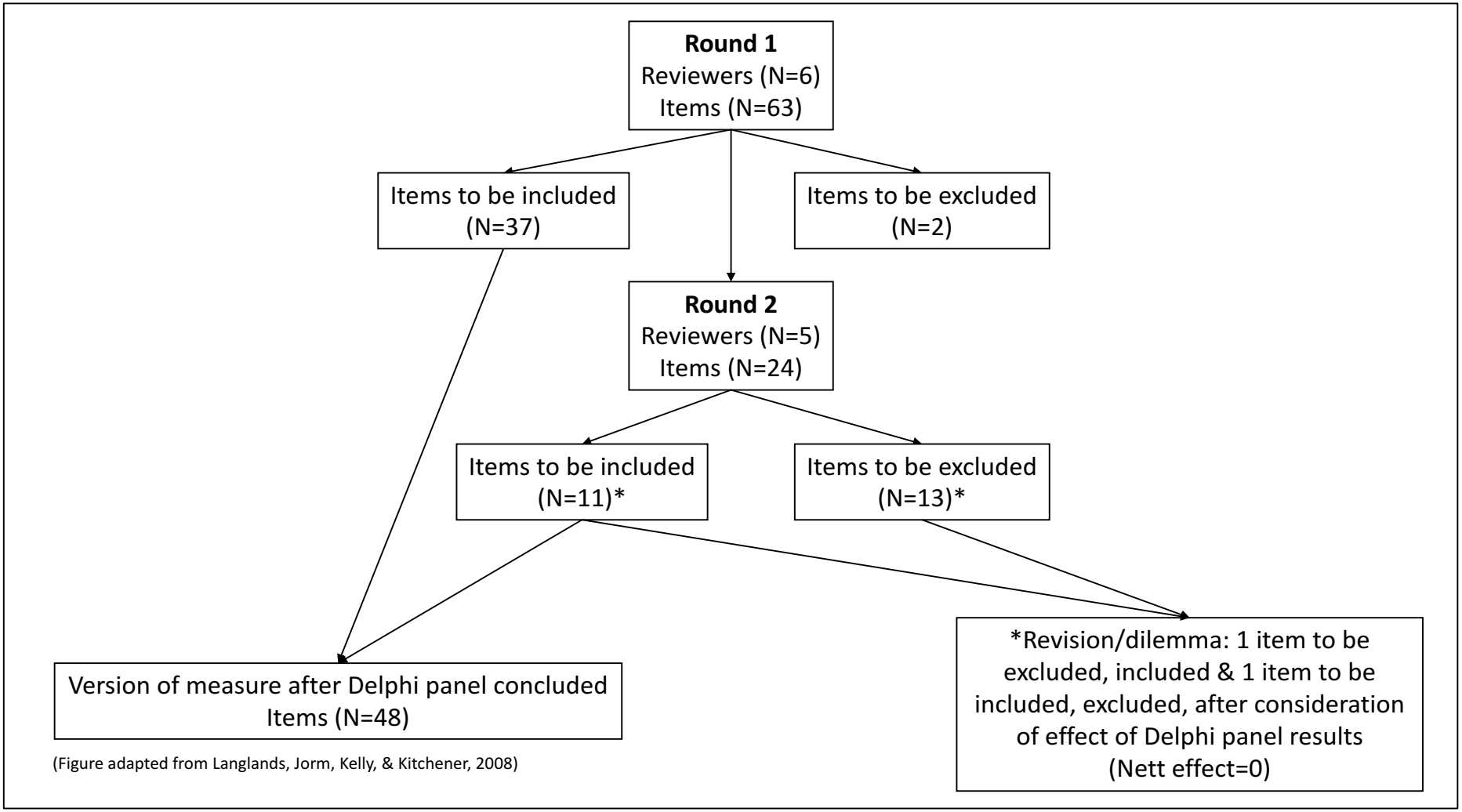

Fig. 3. Process followed with the Delphi expert consensus method.

Secondly, while the Delphi process was underway and on advice from the psychometry expert in the first step, we requested a South African clinical psychologist with an interest in recovery, to match items of the measure, that we had randomly ordered, with the recovery dimensions and their descriptions. This was so we could determine whether the items seemed to relate to the dimensions that we intended. The clinical psychologist could match 39 of the 63 items with their dimensions.

The remaining 24 items, that were not matched, the feedback and comments of the Delphi panel and the earlier issues about abstractness and wording of some items, raised by the psychometry expert in the first step, were used to adapt the measure through clarification of items by changing or amplifying the wording of items, making the items more concrete, moving items from one dimension to another, changing the name of one of the response options, and added descriptions of the response options and an example statement at the start of the measure. After these changes, the second version of the measure was constructed and it consisted of 48 items. (As supplemental material, the items of the second version can be compared in a table format to the first version and the subsequent two versions.) (For reviewers: see the table provided.)

3.4. Content validity: part 2 - Cognitive interviews and matching of items and dimensions

The fourth step in development consisted of two parts, cognitive interviews with service users from the study population and a further round of matching of randomly-ordered items and dimensions, this time by clinical experts, being service providers who worked with the study's service user population at the time.

Cognitive interviews were conducted with four service users from the study hospitals, to determine the suitability and appropriateness of the measure's instructions, the item content and the format (Boateng et al., 2018; Drapalski et al., 2012). Cognitive interviewing is a process whereby a small number of respondents, in this case service users, are

interviewed individually by the researcher, before administration of the measure to a large sample of respondents for reliability testing, to examine the service users' process of thinking about and responding to the items and to determine whether items and response categories are relevant and clear (Peterson et al., 2017). We wanted to determine whether items would be understood by the respondents, during future reliability testing, as intended during development of the measure, as well as whether the items were clearly formulated, the response options sufficient and suitable and the overall format of the measure acceptable to respondents (Boateng et al., 2018; Peterson et al., 2017). Because of time constraints and limited resources, we followed a simplified version of the step-by-step process explained in Peterson et al. (2017) - we identified the intent behind each item and created verbal probes beforehand and used the thinking-aloud procedure and verbal probes during the interviews. The participants, who were service users included in the qualitative part of the study approximately 12-18 months before. As such they were familiar with the first author and the study, which assisted with rapport. Unfortunately, we were only able to include one gender, male, since there were no participants of other genders available for the cognitive interviews at that stage. All participants could read and comprehend English, although for some it was a second language. All four participants were in residential care at their respective hospitals (at least >2.5 years) and they had been living with either major depressive disorder, schizophrenia or schizoaffective disorder for at least 11 years. The first author was well aware that 48 items needed to be discussed during the interviews, which could take a long time, given the instructions by Peterson et al. (2017), and be tiresome for the participants, given that they were taking psychiatric medications which could affect concentration and cause fatigue. The first author found that they were unable to go into depth on every item and, thus, with some items they relied on cues by the participants to gauge their

understanding and intent, to move the process along and not prolong it too much for the sake of the participants.

Despite these challenges, we received constructive feedback from participants and adapted the measure by eliminating 9 items (leaving 39 items). We changed the wording of some items to better align our intent with the participants' understanding (and possibly the understanding of the potential population as a whole, of which they were fairly representative) in order to promote clarity and we repeated the description of each response option at the top of each page of the measure, to ensure ease of reference for future respondents. Although only four participants took part, we did notice some data saturation took place as the interviews progressed. For instance, more than one participant identified confusion with the same items or regarded the same items as overlapping and in need of elimination.

The inclusion of service users and service providers in the content validation process created diversity in perspectives and expertise (experts by experience and professional experts) and as such it was attempted to address the problem of representation bias that has been raised as a possible issue in respect of the Delphi method in the literature (Bloor and Wood, 2006). Unfortunately, time constraints did not allow us to include the perspectives of carers.

After the cognitive interviews, we discussed the measure with the psychometry expert from the first step again and eliminated another item on his recommendation, thus leaving 38 items.

For the second round of matching of items and dimensions, we requested eight service providers from the three study hospitals to perform this task. Five of the service providers (a psychologist, two psychiatrists, a nurse and an occupational therapist) were able to take part. The results identified three items that had no support for their original

dimension. Two of these three items overlapped with four items with at least 60% support for a single other dimension. We moved one of these two items, *I am doing positive things that I did before*, to the other dimension that received 60% support from the participants, namely Adapt and Hope. We decided to retain the other of the two items, *I have purpose in my life*, in its original dimension. From the results of this process, changes were also made to some sub-dimensions. We changed the content of the dimension, Income, Independence, Trust, Agency and Capacity, to not include Trust. This was an issue that came up in the Delphi process and re-emerged in this part of the process. We moved Trust to the first dimension, Relationships with others, so that it consisted of three sub-dimensions, Connection, Support and Trust. We then moved the item, *Other people trust me* to the first dimension to be in line with this change. We also changed the sub-dimension of meaning in dimension four, *Relating to the world*, to purpose, to incorporate participants' feedback that purpose is more descriptive than meaning in the study context and eliminated the sub-dimension of insight, which ultimately, as a result of the changes through the stages, was encompassed by dimension seven. Changes to the sub-dimensions are presented in Table 2.

Table 2

Changes to sub-dimensions through the process of measure development.

	Dimension	**Original sub-dimension**	**New sub-dimension**
Dimension 1	Relationships with others	Connection and Support	Connection, Support and Trust
Dimension 2	Moving positively forward	Adapt and Hope	No change
Dimension 3	Relationship with self	Identity, Routine and Renewal	No change
Dimension 4	Relating to the world	Meaning, Faith, Contribution and Insight	Purpose, Faith and Contribution
Dimension 5	(Re-)gaining of strengths	Income, Independence, Trust, Agency and Capacity	Income, Independence, Agency and Capacity
Dimension 6	Awareness of difficulties	Challenges and limitations	No change
Dimension 7	Clinical understanding to support personal recovery	No sub-dimension/s	No change

3.5. Readability test and final check

As the fifth and last step, we subjected the final version of the measure to a readability test. Several studies in the South African context have used tests to determine the readability of various types of texts, including health information pamphlets (Joubert and Githinji, 2014; Krige and Reid, 2017; Sibanda, 2014). Various commonly used readability tests, for example the SMOG Index, the Gunning Fog Index, the Flesch-Kincaid Grade Level, Flesch Reading Ease, Linsear Write Formula, Fry Readability Graph, Automated Readability Index and the Coleman-Liau Index, exist and have been employed in research (Balogun et al., 2010; Kasule, 2011; Krige and Reid, 2017; Joubert and Githinji, 2014; Sibanda, 2014). The Microsoft Word functionality, calculating the Flesch-Kincaid Grade Level and Flesch Reading Ease score, has also been employed in research to determine the readability of psychometric instruments to assess attitudes towards HIV/AIDS in young adults in South Africa, the United States of America and Turkey (Balogun et al., 2010). Krige and Reid (2017) reported that the Flesch Reading Ease and Fry Readability Graph has been used in readability tests for various health texts in English. Sibanda (2014) used an online method (Readability Formulas, n.d.), for calculating the readability scores on various commonly used readability tests.

Based on this literature, in particular Krige and Reid (2017), we elected to use a combination of the Flesch Reading Ease score and the Fry Readability Graph to determine the readability of the final version of the measure. The first author uploaded the full text of the recovery measure, which included the heading, introduction, instructions, response options and descriptions, example statement, items and concluding sentence. The readability scores were 66.4 for the Flesch Reading Ease and seventh grade for the Fry Readability Graph (Readability Formulas, n.d.). The Flesch Reading Ease scores from 0 (very confusing) to 100 (very easy). With the Fry Readability Graph the average number of sentences per 100

words and the average number of syllables per 100 words are plotted. Based on the result and Fry's theory, a conclusion is drawn about the school grade appropriateness of the text.

Based on the above scores, readability of the measure by a person who had received schooling up to the seventh or eighth year was achieved. Although a very small sample of four, the service users who participated in the cognitive interviews all had some high school, i.e. grade 8 or further, education. Based on this result, we regarded the readability of the measure as sufficient and no changes were made to the grammar or formulation of text of the measure.

As a last step, the first author re-read the final version of the measure, together with the dimensions and their descriptions to ensure, despite changes made, that items were still contained in dimensions that were suitable and that each item in a dimension matched to the description of that dimension.

4. Discussion

Through the content validation process, we adapted the measure evermore to provide for parsimony, functionality and internal consistency as far as possible (Netemeyer et al., 2003; Spector, 1992). The content validation started with a Delphi panel and matching of items and dimensions, through which the items in the measure were reduced from 63 to 48. Next were cognitive interviews with service users, through which the items were reduced to 39 items, and recommendations by a psychometry expert, which led to one other item being eliminated, bringing the final number of items to 38. A last round of matching of items and dimensions did not lead to any items being eliminated, but the content of some sub-dimensions were re-arranged and some items were moved from one dimension to another. The details of the full changes can be viewed side-by-side in the supplemental material made available online. (For reviewers: see the table provided).

4.1 Challenges

It is important to be cognisant of the fact that much time and patience is needed in the development of a measure. The amount of time needed to develop a measure may be underestimated as well as the challenges that may be encountered in the process. The time needed for ethical approval initially, and after certain steps in the process, must be factored into the planning. This can add unanticipated additional time to the study duration.

It is also necessary to take note that recommendations from a Delphi panel may not align with data results and this can pose a challenge for the researcher in deciding about items. Also, novice measure developers might find that formulating items can bring about unanticipated difficulties in being clear, unambiguous and concrete. Meaningful involvement of service users in this process is necessary as well as asking for their input through several iterations of the measure during development, which will assist in developing items that will hopefully be clear, unambiguous and concrete for a broad range of service users. The inclusion of service users in measure development, especially in developing settings such as South Africa, is also very important to provide a voice to an often-marginalised group of persons and to give them the opportunity to contribute to research that is embarked upon by others (researchers), yet intended for their benefit. In this process, it is once again vital that researchers allow sufficient time to include service users who may be faced with challenges in concentration and fatigue due to medication or illness, yet have valuable contributions to make.

4.2 Conclusion

This is the first individual mental health recovery measure developed for the South African context. A rigorous process to develop and initially validate the content was followed and resulted in a preliminary 38-item version of the measure. Further testing of the measure

to fully evaluate it psychometrically to determine its validity and reliability is required as the next step.

Supplementary materials

Table to compare the changes over various versions of the measure. (For reviewers: see the table provided at the end of/with the manuscript)

CRediT author statement

Anneliese de Wet: Conceptualization, Methodology, Formal analysis, Investigation, Resources, Data curation, Writing - Original draft, Visualization **Chrisma Pretorius:** Methodology, Formal analysis, Validation, Writing - Review & Editing.

Ethical statement

Compliance with Ethical Standards: We obtained approval from Stellenbosch University's Research Ethics Committee: Human Research (Humanities) (Reference number PSY-2017-1711) and the Western Cape Provincial Department of Health (Reference number WC_201801_032).

Informed Consent: The study was explained to all participants, who were required to sign informed consent forms.

We obtained permission from the developers of existing measures to use these measures for development purposes in our research.

This manuscript is not under consideration for publication in any other journal, nor has any portion of the manuscript been published previously.

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Declaration of Competing Interest

The Authors declare that they have no conflicts of interest.

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	Version I	Version II (Delphi panel)	Version III (Cognitive interviews)	Version IV	Version V (final)	Dimension (final)
Introduction	This document contains a list of statements about how you might think and feel about yourself, your health, your life and your environment. By completing it you will help us to understand more about the process of your mental health recovery. The process of recovery is different for each person, so there are no right or wrong answers. By completing this document, we hope that the results will also help you to understand more about your own recovery process.	This is a list of statements about how you might think and feel about yourself, your health, your life and your environment. By completing it you will help us to understand more about the process of your mental health recovery. The process of recovery is different for each person, so there are no right or wrong answers. By completing this, we hope that the results will also help you to understand more about your own recovery process. Please use the results from this to discuss and/or plan your mental health recovery with your service provider or people close to you that you trust.	Mental health recovery is a process to: • Find meaning and hope in one's life • Find ways to re-connect with and • Contribute to one's community even if one is faced by mental health challenges. This is a list of statements about how you might think and feel about yourself, your health, your life and your environment. By completing it you will help us to understand more about the process of your mental health recovery. The process of recovery is different for each person, so there are no right or wrong answers. We hope that the results will also help you to understand more about your own recovery process. Please use the results to discuss and/or plan your mental health recovery with your service provider or people close to you that you trust.	No change	No change	N/A

	Version I	Version II	Version III	Version IV	Version V (final)	Dimension (final)
Instructions	How much do you agree with each statement below? (Read and think about each statement carefully. Use the boxes on the right to mark the answer that best fits each statement for you. Only mark one box per statement. Please do not skip any statements.)	Same instructions as version I, but added: **Example statement:** *Through my mental health recovery, I have learnt about my strengths and weaknesses.*	Instructions: How much do you agree with each statement below? (Read and think about each statement carefully. Answer from your own perspective or point of view and from your own experience. Use the boxes on the right to mark the answer that best fits each statement for you. Only mark one box per statement. Please do not skip any statements.) **Go through the example below before you start:** (same example as in version II)	No change	No change	N/A

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimension (final)**
Likert scale	1 = Not at all; 2 = A little bit; 3 = Somewhat; 4 = Quite a bit; 5 = Completely	Same response options as version I, but added descriptions for each option: 1 = Not at all (*I don't agree with the statement in any way*); 2 = A little bit (*I agree with the statement to a small degree*); 3 = Somewhat (*I agree with the statement more than a little bit, but not yet a lot*); 4 = Quite a bit (*I agree with the statement a lot, but not completely*); 5 = Completely (*I agree with the statement in every way*)	No change	No change	No change	N/A
	Items					
1	I feel a (re-)connection with others	I feel a connection with others that support me.	No change	I feel connected to people who support me.	No change	1
2	I (can) communicate with others	I communicate with others.	I communicate with other people in general.	In general, I communicate with people.	No change	1
3	I (can) interact with others	I interact with others.	- [a]	-	-	-

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimension (final)**
4	I (can) get along with others	I get along with others.	I get along with other people in general.	In general, I get along with people.	No change	1
5	I feel a (re-)connection to my community	I feel a positive connection to my community.	No change	I feel positively connected to a community.	No change	1
6	I feel like a person who is part of my community	I feel like I am part of my community.	I feel like a member OR I am part of OR I belong in my community.	I feel part of a community.	No change	1
7	I feel that I am supported	-	-	-	-	-
8	I feel that I am supported by others	I feel that I am supported, emotionally, financially or otherwise, by others.	I feel that I am supported (for example emotionally, financially or otherwise) by others.	I feel supported by others.	No change	1
9	I feel understood (by others)	-	-	-	-	-
10	I provide support to others	I support others, either emotionally, financially or otherwise.	I support others (for example emotionally, financially or otherwise).	I support others.	No change	1

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimension (final)**
11	I feel that I inspire others	-	-	-	-	-
12	I feel that I can be a role model to others	I feel that I am a role model to others because of my mental health recovery.	I feel that others can look up to me because of my mental health recovery.	I feel that people can look up to me because of my mental health recovery.	No change	1
13	I feel like I have adjusted to my mental illness	-	-	-		
14	I feel like I have adjusted to my situation	I feel like I have adjusted to my mental health situation.	I feel like I have adjusted to OR accepted my mental health situation.	I have adjusted to my mental health situation.	No change	2
15	I feel like I am making progress	I feel like I am making progress with my mental health recovery.	No change	I am making progress with my mental health recovery.	No change	2

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimension (final)**
16	I feel like I am moving forward with my illness	I feel like I am moving forward with how I live with my mental health recovery.	-	-	-	-
17	I am thinking in a positive way	I am thinking in a positive way about my mental health.	No change	I think in a positive way about my mental health.	No change	2
18	I feel like I can go on	-	-	-	-	-
19	I can take small steps, into the future	I set goals for my future.	-	-	-	-
20	I can make plans (again) for the future	I make plans for my future.	No change	No change	No change	2
21	I feel a (re-)connection with myself	I understand myself better through my mental health recovery.	No change	No change	No change	3
22	I feel like I am loved	-	-	-	-	-
23	I have a role to play as a person	I feel I have a place in my community.	-	-	-	-
24	I have a routine	I have a routine for my daily tasks.	No change	No change	No change	3

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimension (final)**
25	I feel like I have a new life (ahead of me)	I feel like I have a new life ahead of me. (Moved from dimension 3 to dimension 2)	I feel like I have a new life ahead of me because of my mental health recovery. (Moved from dimension 3 to dimension 2)	No change	No change	2
26	I am taking part in things that I did before	I am doing things (like hobbies, interests, or social activities) that I did before.	I am doing positive things (for example hobbies, interests, or social activities) that I did before.	I am doing positive things that I did before.	No change to wording. (Moved from dim 3 to dim 2)	2
27	I am even doing more things than I did before	I am doing new things.	No change	No change	No change	3
28	I feel again like the person I was before my mental illness	-	-	-	-	-
29	I have meaning in my life	Same as in version I	-	-	-	-
30	I have purpose in my life	Same as in version I	Same as version I	Same as version I	Same as version I	4
31	My faith/belief/religion/prayer helps me	Faith/belief/religion/prayer/spirituality helps me.	No change	No change	No change	4

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimension (final)**
32	My faith/belief/religion/prayer helps me to not feel alone	-	-	-	-	-
33	I can live a normal life	-	-	-	-	-
34	I can contribute to society	I feel that I contribute to society in positive ways.	No change	I contribute to society in positive ways.	No change	4
35	I can acknowledge that I have a mental illness if I want to	-	-	-	-	-
36	I accept my mental illness	-	-	-	-	-
37	I know myself, who I am	Through my mental health recovery, I have learnt about myself.	No change	-	-	-
38	I know about my mental illness	I have information about my mental illness. (Moved from dimension 4 to dimension 6)	No change	I have information about my mental health. (Moved from dimension 4 to dimension 7)	No change	7

	Version I	Version II	Version III	Version IV	Version V (final)	Dimension (final)
39	I am able to identify symptoms early, that can make me sick again	I am able to identify triggers early, that can make me sick again. (Moved from dimension 4 to dimension 7)	No change	No change	No change	7
40	Having a job is important to me	-	-	-		-
41	Earning an income is important to me	Earning an income is important to me.	Earning an income is important to my mental health recovery.	No change	No change	5
42	I have skills that can help me in my life	I have skills that can help me live my life positively.	No change	I have skills that help me live my life positively.	No change	5
43	I have skills that can help me with my illness	I have skills that can help me live positively with my mental health recovery.	-	-	-	-
44	I am responsible for myself	I take responsibility for myself.	I take responsibility for myself OR my own life.	I take responsibility for my own life.	No change	5
45	I can make decisions for myself	I make decisions for myself.	I make decisions about my own life.	No change	No change	5
46	I feel that I am allowed to make decisions for myself	I have good judgement to decide what's good or bad for me.	No change	No change	No change	5

	Version I	Version II	Version III	Version IV	Version V (final)	Dimension (final)
47	I can take initiative to do things	I decide for myself to do things.	-	-	-	-
48	I feel like I am trusted by others	I feel like other people trust me.	No change	Other people trust me.	No change to wording. (Moved from dim 5 to dim 1)	1
49	I can do things that others can do	I feel like I am just as able as other people to do things.	-	-	-	-
50	I feel like I can cope with my mental illness	I feel like I can manage with my mental health recovery.	I feel like I am in control of my mental health recovery.	I feel I'm in control of my mental health recovery.	No change	5
51	I know how to deal with my stress	I feel that I am able to deal with my stress.	No change	I am able to deal with my stress.	No change	6
52	Sometimes I feel like I am recovering and other times I don't feel like I am recovering	Even though recovery has ups and downs, overall I feel like I am moving in a positive direction. (moved from dimension 6 to dimension 2)	No change	No change	No change	2
53	I know my limitations	I know the challenges of my mental health recovery.	I am aware of my own challenges with mental health recovery.	No change	No change	6

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimension (final)**
54	I feel like recovery is difficult	Sometimes I feel like mental health recovery is difficult.	No change	No change	No change	6
55	My environment makes my recovery difficult	Sometimes my environment (like family/friends/work/where I live) makes my recovery difficult.	Sometimes my environment (for example family/friends/work/where I live) makes my recovery difficult.	Sometimes my environment makes my recovery difficult.	No change	6
56	I feel better	I feel better than I did before.	No change	I feel better than I did before. If second or further time completing the questionnaire, answer the following: I feel better than the previous time I completed this questionnaire.	No change	7
57	I feel healed	-	-	-	-	-

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimension (final)**
58	I feel well	-	-	-	-	-
59	I feel it is important for me to take my medication	If I have to take medicine, I feel it is important that I take it.	-	-	-	-
60	If I take my pills (medication), I will recover	I feel that it will help me to recover if I take my medicine.	No change	It will help me to recover if I take my medicine.	No change	7
61	If I have no symptoms, I am recovering from my mental illness	I can still be recovering if I have symptoms.	I can be recovering if I still have some symptoms.	No change	No change	7
62	If I still take medication, I am not recovering from my mental illness	-	-	-	-	-
63	When I get discharged, I don't have a mental illness anymore	Being discharged means I am mentally healthy.	No change	Being discharged means I am mentally healthy.	No change	7
	63 items; 7 dimensions	48 items; 7 dimensions	39 items; 7 dimensions	38 items; 7 dimensions	38 items	7 dimensions

Note. [a] The use of "-" means exclusion of the item from further versions of the measure.

Chapter 7: Discussion and Conclusion

7.1. Introduction

Through this study I have made a contribution to the emerging body of knowledge about mental health recovery in South Africa My overall goal was to develop a contextually appropriate measure of individual recovery for mental health service users in a South African context. I have achieved this goal by pursuing the study objectives. Firstly, I reviewed the literature to gain a thorough grasp on the existing knowledge pertaining to recovery and the measurement thereof, internationally and in South Africa, as well as the overall South African, Western Cape as well as mental health care contexts. By furthermore investigating the understandings and perceptions of recovery, as reported on in the manuscript in Chapter 4, as well as the barriers to, and facilitators of, recovery, reported on in the manuscript in Chapter 5, from the perspective of service users, carers and service providers in a South African context, I was consequently able to develop a measure of recovery that is appropriate for a South African context, as reported on in the manuscript in Chapter 6.

In this chapter I integrate the main findings of the manuscripts developed through this study. I further elucidate the scientific contribution of the study and reflect on my experiences as a researcher in this study. I proceed to point out the limitations of the study as well as the implications and contributions for practice and recommendations for institutional directions and future research from the study. I end the chapter and dissertation with concluding remarks.

7.2. Integration and interpretation of the findings

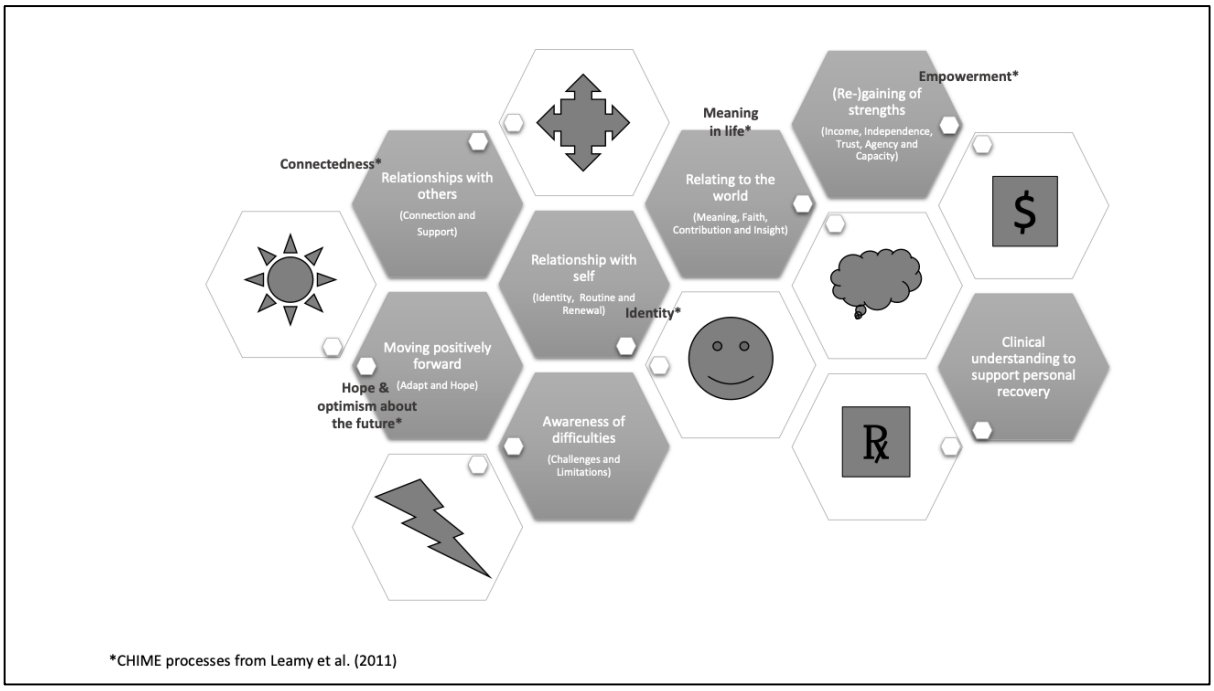
The study consisted broadly of three parts. I will summarise the results from each part and discuss the results to integrate the findings of the study.

In the first part of the study I explored the understandings and perceptions of recovery in a South African context from the perspective of service users, service providers and carers. I obtained the data for this part of the study through qualitative interviews and focus group discussions. I reported on this part of the study in Chapter 4. The results from this part of the study are seven themes with sub-themes for the data, which I subsequently refer to as the dimensions and sub-dimensions of recovery in a South African context. I was able to map five of these dimensions onto the recovery processes of the CHIME framework, while two dimensions remained distinct from the CHIME framework (Leamy et al., 2011).

Figure 7.1 gives a visual overview of the dimensions and sub-dimensions from the first part of the study and indicates those that link to the recovery processes of the CHIME framework (Leamy et al., 2011), by being marked with an asterisk. Figure 7.1 is contained in De Wet & Pretorius (2020b).

Figure 7.1

Visual Overview of Dimensions and Sub-Dimensions with Links to the CHIME Framework



The dimensions were closely linked to each other and thus not mutually exclusive. Some overlap was inevitably found in defining recovery (De Wet & Pretorius, 2020b). The definition of recovery for a South African context, which I ultimately generated from these results, was

> An on-going, gradual, iterative and long-term process for service users (in collaboration with service providers and carers), after being in an acute mental illness state, which may include one or more themes such as relating to self, others, or the world, moving positively forward, (re-)gaining strengths, awareness of difficulties and a clinical understanding to support personal recovery (De Wet & Pretorius, 2020b, p. 8).

The dimension, *awareness of difficulties*, which was generated in the first part of the study, related to challenges and limitations that were experienced as part of the recovery process (De Wet & Pretorius, 2020b). This dimension formed a link to the next objective of the study: the further exploration of the barriers to, and facilitators of, recovery.

In the next part of the study, I explored the barriers to, and facilitators of, recovery in a South African context, once again from the perspective of the same service users, service providers and carers and from the same qualitative data collected through the interviews and focus group discussions as the first part of the study. I reported on these barriers to, and facilitators of, recovery in Chapter 5. From the results in this part of the study I generated themes related to barriers to, and facilitators of, recovery in the study context. The themes related to barriers to recovery that I found to be most salient in the study context were *environment, family*, *public mental health services*, *stigma* and *service users' attitude or behaviour*. The barriers to recovery seemed to result largely from external sources related to interpersonal (family), community, institutional, and societal factors, which variously

intersected. The intersection of recovery barriers and general barriers to persons with mental illnesses who use public mental health services, such as poverty, inequality, the limited resources in society and violence (Schneider et al., 2016), in South African contexts, were deemed to make the recovery for such persons even more complex and challenging than in other contexts. (De Wet & Pretorius, 2020a).

The most important facilitators to recovery that were generated from the results were *support*, *family or friends*, *service providers*, *structure* and *empowerment*. The recovery-promoting facilitators seemed to centre not only around relational factors, predominantly in the form of support, but also around systemic factors through empowerment and structure. The need for support, in fact, was identified as an underlying component to all the themes. The need for support, in turn, also linked closely to the relational nature of many of the dimensions (for example, relating to self, others and the world) from the first part of the study, which, in turn, often had acceptance as an underlying component. (De Wet & Pretorius, 2020a). The need for support referred to both individual-level support, such as peer support work, as well as system-level support, such as the development of environments, i.e., services and communities, that support individual recovery. Recovery is, therefore, facilitated where service users are aided in developing their strength to recover, for instance, through peer support. But, importantly, also in conjunction with enabling environmental factors (Kleintjes et al., 2013). Public mental health departments and services need to look at investing in recovery-enabling environments within their services, which are geared towards the service user to involve them meaningfully in their own recovery (Farkas, 2007), and develop formal peer support work, the latter of which can be used to collaborate with community organisations to work towards more recovery-enabling environments within communities through which other barriers, such as stigma, can be dealt with (De Wet & Pretorius, 2020a). However, services and interventions in public mental health care in South

Africa are not yet formally delivered from a recovery-oriented perspective. The government's recent inclusion in its NMHPF (South African Department of Health, 2013) (refer to section 2.1.6. in Chapter 2 for the details on this) of a reference to the recovery model, and the Ekurhuleni Declaration on Mental Health of April 2012, which refers to a commitment to "fostering [sic] person-centred recovery paradigm that respects the autonomy and dignity of all persons" (p. 50) as a basis for the delivery of their services, is encouraging. This brings hope that recovery-orientation will be formally implemented in public mental health services in the near future. In implementation, specific attention should be paid to the way in which such services should be adjusted, in empowering, meaning-making and hopeful ways (Lloyd et al., 2008), to support recovery optimally. In this way, services could provide an environment with the potential to facilitate the recovery of service users (Lloyd et al., 2008). The results of the study up to this point provided a basis from which to undertake the final part of the study.

In the final part of the study I developed a measure of individual recovery for a South African context. The definition and dimensions of recovery from the first part of the study formed the foundation for the formulation of the items and format of the measure. In addition to the use of the definition and dimensions of recovery, through the literature review which I had conducted initially, I used the international individual recovery measures, which I had identified as robust and having an evidence base, to inform the formulation of the items and format of the measure. In addition, through the literature review, I had gained a better grasp of the context and understanding of the service users for which the measure would be developed. The barriers to, and facilitators of, recovery that were generated from the collected data also contributed to informing the development of the items for, and format of, the measure. Once I had developed the preliminary 63 items for, and format of, the measure, I tested the measure for content validity. I performed content validity by means of (a) Delphi

panel of professional experts, consisting of two rounds; (b) cognitive interviews with four service users; (c) the matching of items and dimensions by clinical experts, over two rounds; and (d) a readability test. The results of the content validity process led me to reduce the items and refine the format of the measure, and move some items from one dimension to another within the measure. The details of the changes to the measure through the various content validity stages are contained in Appendix C20. The measure, called the Measure of Individual Mental Health Recovery for a South African context (MIMHR-SA) finally contained 38 items and is contained in Appendix C21. The results of the content validity process led me to re-arrange the content of some of the sub-dimensions of recovery in the study context. The dimensions and re-arranged sub-dimensions of recovery are presented in Table 7.1.

Table 7.1

Re-Arrangement of Sub-Dimensions through the Process of Measure Development

Dimension		**Original sub-dimensions**	**Re-arranged sub-dimensions**
1	**Relationships with others**	Connection and Support	Connection, Support and Trust
2	**Moving positively forward**	Adapt and Hope	No change
3	**Relationship with self**	Identity, Routine and Renewal	No change

4	**Relating to the world**	Meaning, Faith, Contribution and Insight	Purpose, Faith and Contribution
5	**(Re-)gaining of strengths**	Income, Independence, Trust, Agency and Capacity	Income, Independence, Agency and Capacity
6	**Awareness of difficulties**	Challenges and Limitations	No change
7	**Clinical understanding to support personal recovery**	No sub-dimension/s	No change

To summarise, the main results from the study for a South African context are (a) definition of recovery; (b) dimensions and sub-dimensions of recovery; (c) barriers to and facilitators of recovery; and (d) a measure of individual recovery, the MIMHR-SA. These results from the various parts of the study form a coherent whole and were obtained in a progressive, sequential way, one building on the other. The various parts of the study contributed to answering the research question in the study, how can a contextually appropriate individual measure of recovery for mental service users be developed in a South African context? The first part of the study contributed the definition, dimensions and initial sub-dimensions of recovery in the study. The definition, dimensions and initial sub-dimensions were used, together with the knowledge gained through the literature review and the barriers to, and facilitators of, recovery, to inform the development of the measure of recovery in the last part of the study.

7.3. Scientific contribution of the study

The body of knowledge on mental health recovery in South Africa is still emerging and thus still in need of further future development. In line with the emerging nature of recovery in South Africa, I could find no measure of individual recovery for a South African context before this study was undertaken. Furthermore, no generally-accepted international recovery measure, suitable for adaptation, existed. My initial expectation was also that some of the dimensions of recovery identified in the international research might be found to correlate with local conceptualisations of recovery and this was indeed found to be so. In addition, for participants the dimensions of recovery from international literature, particularly the CHIME recovery processes according to Leamy et al., 2011, at times had different content or practical application (De Wet & Pretorius, 2020b). According to De Wet and Pretorius (2020b), participants also identified additional dimensions of recovery to those proposed by the CHIME recovery processes (Leamy et al., 2011). This confirmed the choice for the overall goal of the study, namely to develop a recovery measure for the local context, as the right one. The main scientific contribution of the study is, thus, that I developed a South African individual recovery measure, the MIMHR-SA. In addition, I tested the measure's preliminary content validity. The content validity results, discussed in the manuscript in Chapter 6, provide some promise of the suitability of the MIMHR-SA for a South African context.

Other scientific contributions of this study are, firstly, that through the exploration of the understandings and perceptions of mental health recovery for service users, carers and service providers and the formulation of a definition and dimensions of recovery, it became clear that the identified dimensions of recovery were closely linked to each other and, for instance, in the case of the sub-dimension of *adapt*, often depended on acceptance of self or the presence of a mental health condition by a service user (De Wet & Pretorius, 2020b).

Likewise, the sub-dimension of *contribution* often depended on acceptance, but, in this instance, of a service user by other persons. Another example of the close link between dimensions is that having an income to be able to provide for themselves or family resulted in hope for some service users (De Wet & Pretorius, 2020b). This, and as stated in De Wet and Pretorius (2020b), confirms the layered, iterative and non-linear nature of the recovery process described before in seminal recovery literature (Deegan, 1988). Furthermore, what I anticipated at the start of the study, stated in De Wet and Pretorius (2020b), and ultimately discovered through the study results, was that the direct applicability of some of the sub-components of the CHIME processes, where they correlated with the study's sub-dimensions, and what they meant for individual participants in the study's context, differed somewhat from other contexts in which the CHIME processes have been applied (Bird et al., 2014; Brijnath, 2015; Piat et al., 2017; Slade, Leamy et al., 2011; Van Weeghel et al., 2019). For example, the sub-component, *Hope and optimism about the future*, of the CHIME processes, which refers to "belief in possibility of recovery", feeling encouraged to change, having role-models, thinking in a positive way and dreaming and aspiring (Leamy et al., 2011, p. 448), seemed to correlate broadly to the study's dimension, *Moving positively forward*, and its sub-dimensions, *Adapt and hope* (De Wet & Pretorius, 2020b). Yet, the related understandings in the specific study context were found to be linked more to older, clinical notions of mental illness, which, in turn, might have indicated the generally underdeveloped mental health context in the broader South African context discussed in the study. (De Wet & Pretorius, 2020b).

Furthermore, the study contributed to understanding how recovery happens (or does not) in the lives of service users by exploring the barriers to, and facilitators of, recovery in a South African context. I found that both intrapersonal and external sources of the barriers and facilitators intersected at times (De Wet & Pretorius, 2020a). Although some barriers to, and

facilitators of, recovery have been examined before in South Africa (Brooke-Sumner et al., 2014; Egbe et al., 2014), through further examination in this study, the emerging body of knowledge on recovery in South Africa was advanced.

7.4. Researcher reflections

A discussion of the study would not be complete without reflecting on myself as a researcher. Braun and Clarke (2019) refer to the process of research as "deliberative" (p. 591), when the researcher contemplates what their approach to the research process is and why they chose that approach, and not only about the nuts and bolts of research, i.e., research design or the methods employed to generate the data. Although this "deliberative process" (Braun & Clarke, 2019, p. 591) refers in the first instance to my relativist ontological and interpretivist epistemological positions, I also understand this to be a process of looking back on the research that was done and how I not only influenced the research process, but how I was influenced by it and how I would do things differently in future because of such reflection (Hollway & Jefferson, 2017).

My interests as a researcher are based on my general interest in the experiences of persons and the voicing of those experiences. Through the stimulation provided by a psychopathology module, which not only focused on diagnostic criteria and the clinical understanding of mental illness, but also incorporated study material on the experiential aspect of psychopathology, this general interest naturally developed into an interest in the experience of mental illness and, hence, I was introduced to mental health recovery as a field of study. The interest in the experience of mental illness, combined with my newly discovered interest in recovery, initiated a Master's degree in psychology, in which I qualitatively explored the lived experience of recovery from first-episode psychosis in schizophrenia in a small sample of service users in South Africa (De Wet et al., 2015). I was fascinated by how service users experience and understand their mental health and how their

own understanding and engagement with their illness (or lack thereof) could help (or hinder) them in their process of dealing with their mental illness. When the need was expressed for a measure of mental health recovery for a South African context, I was eager to conduct the study for a PhD degree. I recognised the chance to develop a recovery measure as an opportunity to contribute to the wider field of mental health recovery that I had become very interested in and advancing my career in mental health recovery research. In the process of becoming increasingly familiar with recovery, I realised that I naturally aligned myself with the foundation of recovery, which is that persons can live their lives in a fulfilling way, despite their mental illness (Anthony, 1993; Deegan, 1988). I also believe all persons find themselves somewhere on a spectrum of mental health and that creating distinctions such as "them and us" (Leader, 2012; Richards, 2010, p. 40) is unhelpful in improving the mental health of individuals and societies.

With this foundation in mind, I approached this study in such a way that I believed in service users being able to contribute meaningfully to the understanding of recovery, and wanted service users to be involved and heard in research about their mental health recovery. This, in part, motivated my choice to include service users in trying to understand what recovery means in the study context. As in other fields of study, the lived experience of the persons at the centre of the topic of interest is increasingly regarded as important, even essential. See, for example, intellectual disability (Corby et al., 2018) and child development (Loxton, 2009). My other motivation for including service users was due to their being the experts by experience of their own recovery, and their inclusion added to the richness of the data generated. Because of the exploratory nature of the study, I included carers and service providers of the service users, to provide a wider perspective on mental health recovery in the study context. However, the inclusion of service users remained a priority.

In including service users as well as carers, I was very aware of the inevitable power imbalance that existed between myself and these participants. I, however, found it difficult to minimise the power imbalance. Although I tried to assure service user and carer participants of my independence from the hospitals where most of the interviews, focus groups and cognitive interviewing took place, tried to speak in plain English, in an inclusive and friendly way, and encouraged participants to call me by my first name, I was not able to truly address the power imbalance. Some service user participants insisted on calling me doctor or nurse. As they did this, I cringed and wished they would not. It made me aware of, and frustrated by, the deeply pervasive imbalance between service user and service provider that impacts on service users' ability to exercise their agency, which is such an important aspect of the (re-)gaining of strengths dimension of recovery from this study. I was also aware that my gender as researcher could impact on the participants' openness in sharing in the encounters, whether it be positive or negative. These experiences of imbalances reminded me to pay specific attention to this dynamic in future studies.

Furthermore, while repeatedly listening to the audio recordings of some of the initial interviews for transcription, I realised to my shame that I had missed some crucial information that some service users had shared. I might have missed this information because of the service users' difficulty with pronunciation, which could have been due to medication side-effects or residual symptoms from their mental illness, or my own nervousness during data collection. I realised that my nervousness might have distracted me from listening intently, thus missing this information. I regretted missing these nuggets of information and the opportunity to ask the participants to elaborate on them. I learnt from these experiences that in future I should pro-actively find ways to approach interviews more calmly, slow down the process and listen more intently.

Not only did the qualitative data collection journal, contained in Appendix C5, form an important trustworthiness check, it was also a very helpful tool in reflecting on the qualitative data collection process for my personal purposes. As the qualitative data collection process progressed, I could contemplate my earlier data collection experiences and keep issues such as imbalances, intentional listening and nervousness in mind in subsequent encounters with participants. Although the journal is a very long document, it provides a comprehensive report on my own process and makes it transparent to others and myself for future studies.

During the data analysis process, I tried to think about what participants did not tell me as well as the reasons for them telling me the things that they did. In some of the encounters with participants, I realised that they sometimes chose to share information that cast them or the services in a positive light. The frustration that I felt with some participants not sharing certain information with me, despite my probing for it, was eased when I read the explanation by Hollway and Jefferson (2017) that perhaps it could be because the participant did not know what reply to give. I am certain that some participants in the study context had never had the opportunity or, perhaps even, the inclination to talk about their mental health experiences, so this was a new encounter for them. I had the impression that they were certainly not stimulated in expressing their experiences in words. I thought that it could also have been because of the systemic influences in institutionalised public mental health services on service user participants, which could have fostered feelings of institutionalisation and learned helplessness and might have incapacitated some service users.

As alluded to earlier, my nervousness, from being an anxious person, could also have influenced the research participants' ease and it certainly influenced my ability to *think on my feet* in encounters with participants during the data collection process. This might also have led to my missing some opportunities for further exploration during these encounters.

In closing, what I learnt from the data collection process was that the process is always *what it is*. It was something that I had learnt during my Master's study and it re-occurred in this study. Although I planned the research and made every effort to proceed with it as rigorously as possible, I was not able to control the data collection process completely and I learnt that I needed to feel comfortable with the process unfolding in the way that it did. This was part of what occurs when we interact with each other. I learnt that I should listen more calmly and intently to research participants, slow myself down during the data collection process and trust myself more within the research process, which can help ease my anxiety, unease, and nervousness. I also realised again that I certainly do not have *the* answers, nor are there perhaps *real* answers to situations, but rather that each person has their own perception of (i.e., answer to) a particular situation. I also learnt that participants are the ultimate experts on their lives and experiences. I discovered that I should stay curious to what I might find in the data collection and analysis process. Even though research is difficult, it is a rewarding process. The world events in 2020 surrounding the Covid-19 pandemic required me to be open to a change of plans in my research process. I was grateful I could navigate these turbulent times and find solutions to dilemmas in my research, created by the pandemic.

Against the background of the Life Esidimeni tragedy in South Africa (for further details, see the report of the investigation by the South African Human Rights Commission, 2019; Breen, 2018) in which more than 100 service users died as a result of "chronic and systemic neglect", "mismanagement" and "dire lack of resources" (South African Human Rights Commission, 2019, p. 2), I realised again through this study the utter importance of not only providing a safe space of caring for service users, but also, importantly, paying attention to and allowing service users to be heard in a respectful, inclusive, compassionate, yet non-patronising, way.

7.5. Limitations of the study

The study had some limitations that I need to point out.

In recruiting service users for the study, I was not permitted direct access to service users, in terms of the ethical permission granted by the provincial Department of Health, and had to rely on service providers at the hospitals to identify service users who met the inclusion criteria and could participate. The implication of this could have been that service providers identified those service users that would present a favourable view of the mental health services and this could possibly have influenced the service user participants' views on mental health recovery that I encountered.

Furthermore, service user participants were mostly in-patient or forensic service users. Although this was a deliberate choice, because generally in South Africa mental health services are mostly still delivered on an institutional basis by psychiatric hospitals (Docrat et al., 2019), it also had a potential drawback, in that a specific representation of mental health recovery could have emerged – one that is representative of institutionalised service users and not community dwelling service users.

The sample of participants in the study was relatively small and representative of a certain region in South Africa, the Western Cape Province. Although it was a small sample and generalisability is limited, the intention with the qualitative enquiries into understandings and perceptions of, and barriers to, and facilitators of, recovery in the study context from three perspectives, service users, carers and service providers, was to provide depth to the results. Such depth would not have been possible with larger numbers given the limited resources at my disposal, i.e., I conducted all the qualitative data collection processes myself due to limited funding. Regarding the location of the study, the Western Cape Province of South Africa, the per capita amount allocated to mental health is the highest in the country (Docrat et al., 2019). This might indicate an important difference in the mental health and

recovery experiences of the study participants, as opposed to persons in other regions of South Africa, and thus impact on the applicability of the results and developed measure to other South African contexts. In future, the study could be replicated in other regions of South Africa to determine whether such results are similar to those in this study.

Through this study I achieved the overall study goal, which was to develop a contextually appropriate measure of individual recovery for service users in a South African context. I followed a rigorous process of developing the measure and tested it for some preliminary content validity, which included presenting the measure in cognitive interviews to a small sample of service users. I wanted to add the administration and testing of the measure to a larger group of service users to further add to the rigour of the study, but due to the Covid-19 pandemic, face-to-face administration of the measure with service users at the study hospitals could not be executed. I considered online administration and discussed it with the staff at the hospitals that formed part of the study, as well as with my supervisor. However, from these discussions I realised that the resources to perform online administration at the hospitals were insufficient, the burden on staff to facilitate such administration, especially in the context of the uncertainties surrounding the pandemic, too considerable and the compromise to service user participant confidentiality unacceptable, to justify the administration. Thus, I decided not to include the administration and testing of the measure. This is a clear limitation of the study and it is my intention to perform the administration and testing in a follow-up study. Although administration and testing did not take place, this did not impact on my ability to answer the research question in the study, by contributing a contextually appropriate measure of individual mental health recovery for a South African context.

7.6. Implications and contributions for practice and recommendations

In addition to the scientific contributions of the study, discussed earlier, the study has potentially contributed in other ways to mental health practice and provides room for recommendations for future research.

The most salient implication and contribution of this study is that the developed recovery measure makes it possible for service users, together with persons involved with their care, such as carers and immediate service providers, to use the results from the administration of the measure as a point of departure for discussions about the recovery process for the service user. The measure was, in the first place, not developed as a clinical tool, which has as its foundation the generalisation of a construct and the assessment of such construct (DeVellis, 2017). This would go against the spirit of the mental health recovery movement, which is focused on the uniqueness of the recovery journey (Anthony, 1993). The intention with the measure was not to be able to classify service users as recovered or not, based on a composite score from all the components of the measure, or to compare results amongst service users. This could likely have the effect of discouraging the service user in their recovery journey if they don't *achieve* through a high score. The development of the measure naturally carries the risk of being used for the aforementioned unintended purposes, which may lead to monitoring, control and the undue exercise of power over service users, which will, in turn, have the detrimental effect of disempowering the affected service users. Although it is impossible for me to avoid such unintended use, I do wish to deliberately caution service providers or other persons administering the measure to not resort to use of the measure for such purposes. The measure was developed primarily to be used in a sensitive and responsible way as a tool, for individual service users to become involved in their own recovery and understand more of how they may want to engage with their recovery process. The scores from the different components or items of the measure should be

discussed with the service user and the service user should be encouraged to celebrate those scores that are higher and supported in finding ways in which they can adjust those scores that are lower, if those components or items are significant or salient to the individual service user. My vision is that the recovery measure can become a conversation tool for service providers in discussing recovery with service users and their carers, or ultimately, as recovery as a term and process becomes more commonplace in discussions in local mental health contexts, as a conversation tool between service users and their carers on their own. If the administration of the measure is repeated over time, service users might find useful information from the scores to determine which areas of their recovery they might want to pay more attention to and work on. The service provider who engages with a service user about their score should understand the service user's own goals as well as their environment, in order for the scores to be discussed in that context and the meaning of the scores to be understood individually. The employment of the measure can be useful to service users to have a better understanding of their own recovery process and to move along in that process.

One of the initial intentions with the development of the measure was to provide recovery-oriented programmes with a means to determine how programme participants are moving along in their recovery journey in order to report to funders, either to obtain funding in the first place or to retain existing funding.

The exploration of the understandings and perceptions, as well as the barriers to, and facilitators of, recovery in this study, contributes to the small, existing body of knowledge on recovery in South Africa (for example, see Bila, 2019; Brooke-Sumner et al., 2014; De Wet & Pretorius, 2020a; De Wet & Pretorius, 2020b; De Wet et al., 2015; De Wet et al., 2019; Gamieldien et al., 2020; Kleintjes et al., 2013; Parker, 2012).

Regarding recommendations from the study, these relate to possible institutional directions and future research suggestions.

The imperative provided by the NMHPF (South African Department of Health, 2013) towards recovery, in order to support service users and their carers to establish recovery in their communities and that services should be delivered in such a way as to support service users to be able to return to, or take up, roles in their community as they choose, creates the hope for the expansion of the small base of existing recovery work in South Africa (for example, see The Spring Foundation, n.d.) and the concurrent development of recovery-oriented services in the public mental health sector. I add my voice to so many others (for example, see Docrat et al., 2019) who have recommended that mental health in public health care budgets must be prioritised. This prioritisation needs to take place so that deliberate and constructive efforts can be made to invest in recovery-orientation and more recovery programmes.

As referred to in the limitations previously, I wanted to add the administration and testing of the measure to a larger group of service users to further add to the rigour of the study. Therefore, I recommend that the measure developed in the study be psychometrically evaluated with a diverse range of persons with lived experience of psychosocial disabilities in the study context to determine how representative and applicable the measure is and to determine the strength of the measure's psychometric properties. Such diverse range of persons should include both hospital and community-based service users.

I think it could also be useful to further analyse the existing data from this study to triangulate those service user, service provider and carer interviews that relate to the same service user. A case study type of design could be used in this analysis process. Such further analysis could provide valuable additional results on how a single case is understood from various perspectives and provide even more depth than the present study in understanding recovery in the study context.

An important recommendation for future research relates back to the choice during the planning of this study to focus on individual recovery, as opposed to recovery-orientation of services. A preliminary understanding of individual recovery has been established through this study and other previous and planned studies (Bila, 2019; De Wet et al., 2015; Gamieldien et al., 2020), but this needs to be complemented by an investigation of mental health care services for their potential to be recovery-oriented (Slade et al., 2014), as recommended in De Wet and Pretorius, 2020b. While the focus on individual recovery of service users is essential, a focus on services that support such individual recovery is, in addition, crucial. These recovery-oriented services must be developed, otherwise service users will continue to face the huge, perhaps insurmountable, existing challenges in services, which will continue to impact negatively on their recovery.

A final important recommendation for both practice and future research stems from the results from the exploration of the barriers to, and facilitators of, recovery. These results identified the need for support on various levels, i.e., individual, social, institutional and societal, for service users in the study. This recommendation is closely linked to the previous recommendation regarding the recovery-orientation of services (Burke et al., 2018b). Yosso (2006), in writing about Black communities and education in the American context, makes an argument for looking at such communities not as lacking in resources, but rather as containing *cultural wealth* (p. 70). I argue that the same can be said of communities in the study context that are served by public mental health services and regarded as poor and under-resourced (as discussed in section 2.1.4 in Chapter 2). I suggest that these communities, served by the public psychiatric hospitals in this study, should not be viewed as solely lacking in mental health resources, but rather as having *mental wealth* that must be uncovered and used in the promotion of recovery for individuals. Given the presence of the need for support from the results of this study and my suggested focus on potential mental

wealth in these communities, I further considered, and recommend, the future investigation and development of peer support work. Peer support work may be a largely untapped *mental wealth* resource in South African contexts.

Peer support work is defined as persons, who have lived experience of recovery from mental illness, aiding other persons facing the same or similar circumstances (Walker & Bryant, 2013). However, peer support work can take place not only informally, through voluntary mutual support, for example, but also formally by peers providing a professional service to other service users for remuneration (Davidson et al., 2006; Walker & Bryant, 2013). In this recommendation, I refer to formal peer support work. Peer support work has a growing evidence-base in mental health care in other settings (Burke et al., 2018a, 2018b). Some peer support work in mental health is starting to come about in some South African settings. For example, Cape Mental Health, a South African non-profit organisation providing mental health services, piloted a peer support programme by providing training, mentoring and debriefing in peer support work to some of their service users (Cape Mental Health, 2019). As concluded in De Wet & Pretorius (2020a), much room exists, however, for the expansion of peer support work through formal regulation of by whom and how it is delivered and evaluated (Vally & Abrahams, 2016), as well as suitable contextual training for peer support workers (Pathare et al., 2018). Peer support work, in the first instance, would support service users in their recovery as it could aide service users, who often have poor social interactions, to improve such interactions (Slade, Williams, et al., 2012) as well as to feel more empowered and hopeful (Trachtenberg et al., 2013) and be provided with role models (Burke et al., 2018a). Given the resource constraints in South African settings (Docrat et al., 2019), peer support work could also provide much needed relief to service providers from the overwhelming burden of care that they carry (De Wet & Pretorius, 2020a).

Furthermore, such peer support work could provide meaningful work and income to the peer support workers (Slade, Williams, et al., 2012). The performance of peer support work might even help to address stigma in communities, by contributing to more widespread mental health knowledge. Lastly, such peer support work could hold financial benefits for health departments in the long run (Moran et al., 2020; Trachtenberg et al., 2013). (De Wet & Pretorius, 2020a).

In a review of the costs and cost-effectiveness of interventions for mental, neurological and substance use disorders in South Africa, Jack et al. (2014) concluded that mental health care should be included in primary care or community services and could also be provided by non-specialised persons. Although this conclusion refers to the so-called task-shifting approach from specialised mental health care workers to non-specialised community mental health workers (Petersen et al., 2010), I suggest it could include peer support work. Non-profit organisations in South Africa, performing advocacy and awareness-raising work by persons with psychosocial and intellectual disabilities about such disabilities (for example, see South African Federation for Mental Health, n.d.), also refer to the peer support work that they do. Ideally, such organisations and South African public mental health services could be important partners in the development of formal peer support work through mutually beneficial collaboration; the organisations providing the human resources and experience and obtaining potentially meaningful involvement for their members, public mental health services demonstrating a definite move towards changing their orientation, and financial resources enabling potentially cost-effective and recovery-contributing interventions for their service users.

However, peer support work is not without challenges and should be implemented with caution in South African settings. Challenges such as discrimination, poor remuneration and challenges in adjusting from being a service user to being a peer support worker have

been identified previously in other settings (Walker & Bryant, 2013). These challenges may be very valid given the generally challenging South African contexts described in section 2.1.4 in Chapter 2. However, South African contexts can learn and stand to benefit from the experiences in other countries where formal peer support work has been implemented before. It would be prudent to take advice from researchers in other settings before implementation of formal peer support work in South African settings. Despite these challenges, I consider the benefits as being potentially greater than the drawbacks, if it is implemented with caution through appropriate selection, proper training and management of peer support workers (Vally & Abrahams, 2016), specification of peer support worker roles, and respect, by specialised mental health care workers, for peer support work as a professional service (Davidson, 2015). Ultimately, such inclusion of peer support work in South African contexts can lead to more authoritative, and thus influential, positions being occupied by persons with lived mental health experience, as advocated for by Byrne et al. (2018).

7.7. Concluding remarks

Through this study I contributed, to the field of recovery, a contextually appropriate measure of individual mental health recovery for a South African context. I hope that the knowledge gained through the study encourages further exploration of recovery in South Africa to add to the emerging body of recovery knowledge, and ultimately benefit and empower service users and their carers to move along in the recovery process.

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Appendices

Appendix A1: De Wet et al. (2019). The Spring Foundation.

De Wet et al. (2019). The Spring Foundation: A recovery approach to institutional public mental health services in South Africa. *Perspective in Public Health, 139*(3), 123–124. https://www.doi.org/10.1177/1757913919838767, including publisher's permission to reproduce.

FEATURE

The Spring Foundation: a recovery approach to institutional public mental health services in South Africa

Recent change in mental healthcare policy in South Africa has promoted a recovery approach to support people with mental health problems within communities and institutions. In this article, Anneliese De Wet and her co-authors share the progress and early successes of The Spring Foundation, one of the first interventions to be developed and based in Cape Town.

Mental health recovery is aimed at developing meaningful and productive self-directed lives by mental health service users[1,2] and mental health services that support such living. The recovery field is well developed internationally, although still emerging in South Africa. The inclusion of recovery as an ideal and value in South African mental healthcare policy in recent years provides for the prioritisation of recovery programmes and initiatives.[3] Few recovery initiatives have been launched in South Africa, especially in the public health sector. One of the only such initiatives was launched at Lentegeur Hospital (LGH) in Mitchells Plain in the Western Cape of South Africa in 2012.[4,5]

BACKGROUND

LGH was established in the 1970s during Apartheid to serve its local population, mostly consisting of marginalised persons from mixed race origin[i] faced with widespread poverty and lack of resources in the form of services and basic needs. Today LGH has 690 inpatient beds and is one of three major public psychiatric hospitals in the Western Cape.[5] LGH provides various mental health services to the wider Western Cape population in South Africa,[5] yet it is still affected by its early stigmatisation as a 'malhuis[ii] in the ghetto'.[6] South Africa is a low-middle income country still facing challenges, such as poverty and resource constraints.[7] Kleintjes et al.[8] regard the relationship between poverty and mental illness as involved in the absence of emphasis on service user recovery in South Africa. South African public mental health services, because of the large demand on limited resources, are mostly institution-based,[9] focus largely on symptom relief,[10] and struggle to address mental health needs. Consequently, many service users return repeatedly to use public mental health services.[6] However, these challenges create opportunities for novel approaches to mental healthcare in South Africa.

In South Africa, few resources and budget allocations are aimed at recovery

THE SPRING FOUNDATION

The Spring Foundation (SF) was founded at LGH in 2012 by the second author, John Parker (J.P.), a psychiatrist at LGH, who identified a need for an alternative or additional approach to the traditional mental health services, and identified recovery as such an alternative or additional approach. In developed settings, recovery is supported by well-equipped resources and budgets that allow service users opportunities to explore recovery options.[11] In South Africa, few resources and budget allocations are aimed at recovery. Despite the ideals of recovery being included in policy documents,[3] few of these have been implemented in services benefitting service users.

The SF employs innovative approaches to mental health, based on the recovery dimensions conceptualised by Jacobson and Greenley.[12] Jacobson and Greenley[12] regard hope (possibility to recover), empowerment (self-determination, fearlessness and taking charge), healing (self-being separate from disease and control) and connection (social involvement and also as a bridge between internal and external dimensions) as the internal dimensions of recovery. The SF incorporated these dimensions into their goal, namely, to establish a sense of hope and recovery for service users through re-connection on various levels, such as the natural world, community, identity and heritage.[4] With this goal as a foundation, the SF offers service users various recovery initiatives to assist in their recovery process.

The SF offers service users various recovery initiatives to assist in their recovery process

Several initiatives are currently implemented by the SF. The flagship project is a market garden, in which service

FEATURE

users learn new skills and work. The market garden provides organic vegetables to high-end consumers and the hospitality industry at a premium, thereby being able to provide the same products to low-income communities, often faced with food insecurities and a lack of fresh produce, at a subsidised rate. Another initiative is an identity document project, assisting service users to obtain an identity document, if they do not possess one, in order to apply for an often much-needed disability grant from the government. The wheelchair maintenance and repair project involves training of intellectually disabled service users to clean and repair wheelchairs, receiving a stipend in the process and learning how to spend the stipend. A creative arts therapy project, aimed at adolescents, consists of music and dance. The t-shirt project creates awareness of stigmatisation of mental illness by printing challenging slogans on t-shirts and selling the t-shirts for funds. The mindfulness project is aimed at training staff to create a deeper awareness of their own experiences.[4] Each of the projects is focused on creating some form of re-connection that was lost: such re-connection assists in the promotion of recovery and hope.

Each of the projects is focused on creating some form of re-connection that was lost

FUTURE WORK

Some of the proposed projects of the SF include a residential placement and care programme, a clothes bank, and a feeding scheme for service users (especially children) who face basic needs insecurities, a container gardening project, a walled garden project, a carbon footprint project and a water footprint project.

In order to justify the continuation of the work of the SF, it is important to determine whether the projects are indeed contributing to the recovery of the service users. Thus, the development of an instrument to measure the individual recovery of service users in the South African context is underway by the first author, Anneliese de Wet (A.D.W.).

CONCLUSION

Anecdotal evidence indicates that the initiatives of the SF are transforming the way that LGH and mental illness are viewed by the communities it serves and are providing a stimulus for the regeneration of these communities by the restoration of hope and identity. This will hopefully pave the way for other recovery initiatives to follow in a country faced with many mental health challenges and a need for novel approaches to overcome them.

CONFLICT OF INTEREST

The authors declare that J.P. is employed as a psychiatrist at Lentegeur Hospital and as such receives remuneration from the Department of Health in the Western Cape Province of South Africa. J.P. is also the founder of The Spring Foundation. As such a conflict of financial interest as well as a competing interest exist between the work reported on in this article and the positions of J.P. The other authors declare no conflict of interest.

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NOTES

i. The term 'mixed race origin' refers to persons who have parents or ancestors from differing ethnicities.
ii. The Afrikaans word for 'madhouse'. Afrikaans is one of the local languages in South Africa, used by many LGH service users.

Anneliese De Wet
Department of Psychology, Stellenbosch University, South Africa
Email: anneliesedewet@sun.ac.za

John Parker
Department of Psychiatry, University of Cape Town, Cape Town, South Africa; Provincial Department of Health, Lentegeur Hospital, Cape Town, Western Cape Province, South Africa

Chrisma Pretorius
Department of Psychology, Stellenbosch University, South Africa

Corresponding author
Annaliese De Wet, as above

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Appendix C1: Interview schedule – service users

Are you ready to start the interview?

Start the audio recorder and advise the participant thereof.

Questions

- If you had to explain to me what *recovery* means to you, what would you say?

  Probes: That is interesting / understandable, could you tell me a bit more about that?

  I hear what you are saying, could you elaborate on that / give me a bit more detail about that?

As I explained earlier, recovery is what I am interested in for this study and recovery is a process to:

- Find meaning and hope in your life
- Find ways to re-connect with and
- Contribute to your community even if you face mental health challenges.

- I was wondering, what I explained now, does it make sense to you or can you connect with that at all? Do you think it is possible to recover from a mental illness?

  Probes: That is interesting / understandable, could you tell me a bit more about that?

  I hear what you are saying, could you elaborate on that / give me a bit more detail about that?

  Can you give me some examples from your own life?

- I was wondering, have you ever heard the word *recovery* being used before like this?

  If so, can you explain a bit more of what was said / how the word was used?

- I was wondering whether you could tell even more now about how *you* understand recovery?

Probes: That is interesting / understandable, could you tell me a bit more about that?

I hear what you are saying, could you elaborate on that / give me a bit more detail about that?

- Have nurses or doctors or any such persons ever talked to you about recovery?

If so, can you tell me what they told you?

Probes: That is interesting / understandable, could you tell me a bit more about that?

I hear what you are saying, could you elaborate on that / give me a bit more detail about that?

- Do you or did you take part in any activities / programmes / interventions at the hospital to help you with your mental illness?
- Could you describe to me how the activities / programmes / interventions works or worked?
- How does or did it make a difference to you and how you are or were feeling?
- Do you feel different now after taking part in the activities / programmes / interventions at the hospital?

Probes: That is interesting, could you describe some more how that feels?

- What would you call / how would you describe where you are now in your life, after feeling ill?

Probe: I would like to understand why you describe it like that, could you explain this to me?

- Do you still feel the same way you did before all this started or do you feel different now?

[If yes, just say ok and move on to the next question]

[If no, ask: how do you feel different?]

Probe: That is interesting / understandable, could you tell me a bit more about that?

[Observe how the participant is doing and consider what information they have already shared and then decide whether to ask all of the following 5 questions or only some / none of them]

- How do you understand where you are and what is happening to you now?
- What does it mean to you to be where you are now?
- How does it feel?
- What do you think about it?
- Why do you think that things are happening the way they are now?

I want to move on and ask you about the things that help and don't help you in the process you are in now:

- What or who helps you to handle your situation at the moment?
- How does/do …… help you?
- What or who helps you the most?
- What or who has not helped you in this process?
- How does/do …… not help you?
- Could you perhaps tell me what you do to help yourself?

  Probe: Could you give me an example of that?
- What do you think you have learnt about yourself in the process that makes you stronger?

  Probe: That is interesting / understandable, could you tell me a bit more about that?

- How has this experience impacted your work?
- And, you family/partner/children?
- And, your social life?
- Who do you enjoy spending time with at the moment?
- Is that different than before?
- Why do you think that is?
- What have you learnt from this experience that will help you in future?

- What do you hope for in the future?
- And since we are done with most of the questions, how do you feel right now?

Conclusion

I think this concludes this interview. Is there anything that you would still like to say, share or ask me?

[If the answer is yes: Please do.]

[If the answer is no, move on to the following paragraph.]

By sharing your experiences and feelings, you have made it possible for me to have a better understanding of how you understand recovery and what helps or does not help you in that process.

Thank you very much for your time and for taking part in this interview and my research project. I hope that it has also been a good experience for you.

Appendix C2: Interview schedule – carers

Are you ready to start the interview?

Start the audio recorder and advise the participant thereof.

Questions

- If you had to explain to me what *recovery* means to you, what would you say?

  Probes: That is interesting / understandable, could you tell me a bit more about that?

  I hear what you are saying, could you elaborate on that / give me a bit more detail about that?

As I explained earlier, recovery is what I am interested in for this study and recovery is a process to:

- Find meaning and hope in your life
- Find ways to re-connect with and
- Contribute to your community even if you face mental health challenges.

- I was wondering, what I explained now, does it make sense to you or can you connect with that at all? Do you think it is possible to recover from a mental illness?

  Probes: That is interesting / understandable, could you tell me a bit more about that?

  I hear what you are saying, could you elaborate on that / give me a bit more detail about that?

  Can you give me some examples from your own life?

- I was wondering, have you ever heard the word *recovery* being used before like this?

  If so, can you explain a bit more of what was said / how the word was used?

- I was wondering whether you could tell even more now about how *you* understand recovery?

Probes: That is interesting / understandable, could you tell me a bit more about that?

I hear what you are saying, could you elaborate on that / give me a bit more detail about that?

- Have nurses or doctors or any such persons ever talked to you or your family member / love one about recovery?

If so, can you tell me what they told you?

Probes: That is interesting / understandable, could you tell me a bit more about that?

I hear what you are saying, could you elaborate on that / give me a bit more detail about that?

- Does your family member / loved one take part in any activities / programmes / interventions at the hospital to help with their mental illness?
- Could you describe to me how the activities / programmes / interventions works or worked?
- How does or did it make a difference to them and you?
- What would you call / how would you describe where your family member / loved one is now in their life, after feeling ill?

Probe: I would like to understand why you describe it like that, could you explain this to me?

[Observe how the participant is doing and consider what information they have already shared and then decide whether to ask all of the following 5 questions or only some / none of them]

- How do you understand where your family member / loved one is and what is happening to them now?
- What does it mean to you for them to be where they are now?
- How does it feel?
- What do you think about it?

- Why do you think that things are happening the way they are now?

I want to move on and ask you about the things that help and don't help you and your family member / loved one in the process you both are in now:

- What or who helps your family member / love one and yourself to handle your situation at the moment?
- How does/do …… help you both?
- What or who helps you both the most?
- What or who has not helped you both in this process?
- How does/do …… not help you both?
- Could you perhaps tell me what you both do to help yourselves?
  Probe: Could you give me an example of that?
- What do you think you have learnt about your family member / loved one and yourself in the process that makes you stronger?

  Probe: That is interesting / understandable, could you tell me a bit more about that?

- How has this experience impacted your family member's / loved one's / your work?
- And, your family/partner/children?
- And, your family member's / loved one's / your social life?
- Who does your family member / loved one / you enjoy spending time with at the moment?
- Is that different than before?
- Why do you think that is?
- What have you learnt from this experience that will help you and your family member / loved one in future?
- What do you and your family member hope for in the future?
- And since we are done with most of the questions, how do you feel right now?

Conclusion

I think this concludes this interview. Is there anything that you would still like to say, share or ask me?

[If the answer is yes: Please do.]

[If the answer is no, move on to the following paragraph.]

By sharing your experiences and feelings, you have made it possible for me to have a better understanding of how you understand recovery and what helps or does not help you and your family member / loved one in that process.

Thank you very much for your time and for taking part in this interview and my research project. I hope that it has also been a good experience for you.

Appendix C3: Interview schedule – service providers

Are you ready to start the interview?

Start the audio recorder and advise the participant thereof.

Questions

- If you had to explain to me what *recovery* means to you, what would you say?

  Probes: That is interesting / understandable, could you tell me a bit more about that?

  I hear what you are saying, could you elaborate on that / give me a bit more detail about that?

As I explained earlier, recovery is what I am interested in for this study and recovery is a process to:

- Find meaning and hope in your life
- Find ways to re-connect with and
- Contribute to your community even if you face mental health challenges.

- I was wondering, what I explained now, does it make sense to you or can you connect with that at all? Do you think it is possible to recover from a mental illness?

  Probes: That is interesting / understandable, could you tell me a bit more about that?

  I hear what you are saying, could you elaborate on that / give me a bit more detail about that?

  Can you give me some examples from your own life?

- I was wondering, have you ever heard the word *recovery* being used before like this?

  If so, can you explain a bit more of what was said / how the word was used?

- I was wondering whether you could tell even more now about how *you* understand recovery?

Probes: That is interesting / understandable, could you tell me a bit more about that?

I hear what you are saying, could you elaborate on that / give me a bit more detail about that?

- Do you find that people ever talk about recovery here at the hospital?

If so, can you tell me what they say about it?

Probes: That is interesting / understandable, could you tell me a bit more about that?

I hear what you are saying, could you elaborate on that / give me a bit more detail about that?

- Do you know of any activities / programmes / interventions at the hospital to help with service users' mental illness?
- If so, could you describe to me how the activities / programmes / interventions works?
- How do you think it makes a difference to the service users and their carers?

I want to move on and ask you about the things that help and don't help service users and their carers in the process of recovery that they find themselves in:

- What or who helps the service user and carer to handle their situation of a mental illness diagnosis?
- How does …… help them?
- What or who do you think helps them the most?
- What or who do you think has not helped them in this process?
- How does …… not help them?
- Could you perhaps tell me what you think they do to help themselves?

  Probe: Could you give me an example of that?
- What do you think service users and carers might have learnt about themselves in the process that perhaps makes them stronger?

Probe: That is interesting / understandable, could you tell me a bit more about that?

- How do you think this experience might have impacted on service users' / carers' work?
- And, their family / partner / children?
- And, their family member's / loved one's / social life?
- Do you think that is different than before for them?
- Why do you think that is?
- What do you think are the things that service users and their carers hope for the future?
- And since we are done with most of the questions, how do you feel right now?

Conclusion

I think this concludes this interview. Is there anything that you would still like to say, share or ask me?

[If the answer is yes: Please do.]

[If the answer is no, move on to the following paragraph.]

By sharing your experiences and feelings, you have made it possible for me to have a better understanding of how you understand recovery and what helps or does not help in that process.

Thank you very much for your time and for taking part in this interview and my research project. I hope that it has also been a good experience for you.

Appendix C4: Focus group interview guide

(All participants: English)

Are you ready to start?

Start the audio recorder and advise the participants thereof.

Questions

[Consider, while asking the questions, what information the participants share and then decide whether to ask all of the questions or only some of them.]

- If you had to explain what *recovery* means, what would you say?

Recovery is what I am interested in for this study and recovery is a process to:

- Find meaning and hope in your life
- Find ways to re-connect with and
- Contribute to your community even if you face mental health challenges.

- I was wondering, what I explained now, does it make sense to you or can you connect with that at all? Do you think it is possible to recover from a mental illness?
- I was wondering, have you ever heard the word *recovery* being used before?

  If so, can you explain a bit more of what was said / how the word was used?

- Do you find that people ever talk about recovery here at the hospital?

  If so, can you tell me what they say about it?

- Do you know of any activities / programmes / interventions at the hospital to help with service users' mental illness?
- If so, could you describe to me how the activities / programmes / interventions works?
- How do you think it makes a difference to the service users and their carers?

I want to move on and ask you about the things that help and don't help service users in the process of recovery:

- What or who helps the service user and carer to handle their situation of a mental illness diagnosis?
- How does …… help them?
- What or who do you think helps them the most?
- What or who do you think has not helped them in this process?
- How does …… not help them?
- What do you think are the things that service users and their carers hope for the future?

[All the questions above are dependent on the results from the interviews. I might have to leave out / add in some questions based on the results. I will only be able to tell that when I finalise the initial analysis of the interviews.]

I would also like to briefly share with you what I understand about what interview participants shared with me about recovery.

[Share a brief overview of the initial interview results.]

You are involved in an ongoing or direct way in the process of recovery (either as service user / carer / service provider), so your contributions is valuable to me and will help me to work out whether I understood the interview participants correctly. So, please do let me know if you think that my interpretation is off the mark – I would appreciate that very much!

[Allow participants to share their opinions about the initial results from the interviews until it is clear that there are no more contributions.]

Conclusion

I think this concludes the focus group. Is there anything that you would still like to say, share or ask me?

[If the answer is yes: Please do.]

[If the answer is no, move on to the following paragraph.]

By sharing your experiences and feelings and thoughts, you have made it possible for me to have a better understanding of how you understand recovery and what helps or does not help in that process and whether I am on the right track in my research.

Thank you very much for your time and for taking part in this focus group and my research project. I hope that it has also been a good experience for you.

Appendix C5: Qualitative Data Collection Journal

In this journal, I describe the interactions I had with some participants – service users, carers and service providers - to collect data. I give a description of the participant, who they were and what they brought to the interaction, the context for the participant, if available, and the context of the interaction, as well as what stood out for me from the interaction with them. I also describe my reflections on myself in my interactions with the participants. This is a long journal, 48 pages, but I felt I needed to give each participant a voice to express the experiences of the participants in the study context, which are marked by resource constraints, poverty, adversity, challenges and struggles. Whether service user, carer or service provider, each had to traverse a multitude of obstacles in their journey within their spaces and I felt it necessary, in the spirit of recovery, to let their voices be heard, at least, in this way. I realise the participants' voices are filtered through my experience of them and where I am as well as where I come from, but I feel this journal at least captures something of the participants, which would otherwise be lost. The participants, especially the service users and carers are persons who are often not heard often. I also felt it important to give expression to my own experiences within the research space with them, to complete the picture of our interaction and what it meant for me.

Introductory Meetings at Hospitals

26 April 2018 at 12:00 - Hospital 3

I met with the Department of Health's appointed contact person. She was a clinical psychologist, who came across as very friendly and kind, but a bit unsure as to how she could help me and what I required from her or the hospital. I felt a bit deflated, as I had hoped that she would know about my study, since I assumed the hospitals were informed of my study by the Department of Health. I tried to explain my study and she explained how the hospital

works. It felt a bit overwhelming and uncertain to me at first, to wrap my head around it all. However, she was very accommodating and made me feel at ease and welcome. She took me to the residential wards at the hospitals, as she felt that I might find the most suitable participants for my study there. I met one of the nurses and he took over from her in explaining how the residential wards work, which it seemed help her to understand more about the wards herself too. I found this interesting. The nurse was very knowledgeable, extremely helpful and very passionate about his work. He said that he was excited that I was interested in doing work on mental health recovery, since he was also interested in the field. This made me feel more excited than before and I felt a connection with him. His explanations of how their services work, gave me some valuable insight into the public mental health services. I was grateful to have met him and felt some success on my first day in the field.

It felt good to have had made a start with the data collection. I wanted to keep reminding myself to ask the questions, that I have, and get a proper sense for the place before I start with the data collection. The organisational structure is also important in understanding what happens there in terms of recovery/support/care. The understanding is also important for me and how I work.

Between my visit to Hospital 3 and Hospital 2, I was negotiating access with Hospital 2 and Hospital 1, which felt to me like a never-ending process.

6 June 2018 at 15:00 - Hospital 2

I met with the contact persons, two clinical psychologists (one male/one female), at the hospital's out-patient department. They were both very kind and accommodating, interested in my research and put me at ease quickly. They were, like the psychologist at Hospital 3 unsure of how they could help me. I started to think that this was how it would go throughout the research process. They were very clear and helpful in explaining how the

hospital works and is organised, which gave me clarity for my planning and put me more at ease. They suggested wards that I could source participants from, this helped me.

Afterwards, one person offered additional help with my research in exchange for authorship on publications. I politely said that I would think about it, but could not promise anything. The suggestion made me feel somewhat uncomfortable.

15 June 2018 at 10:30 - Hospital 1

I had arranged to present my research plan to staff of the unit where I would be allowed to collect my data. After the presentation, I met some of the psychiatrists and psychologists in the unit, one of which was also interested in recovery, the idea of which made me feel excited. There were approximately 15 staff present, many of which were the heads at the various wards and others from various disciplines. I did not meet everyone. I was mostly asked questions about inclusion criteria. The head of the unit offered to send out an email to staff to ask them for possible participants and their own participation.

25 June 2018 at 12:30 - Presentation at Hospital 3

Upon arrival, I met with the head nurse and explained my research to him in more detail. He also introduced me to the staff in the office. He then took me to their boardroom to set up for the presentation. I met several staff; nurses, occupational therapists, psychiatrists and social workers at the presentation. One of the psychiatrists made me feel very nervous by pointing out several limitations of my study. Some staff indicated possible service user candidates for my study, which was helpful and made me feel like they were committed to assist me with my research. One staff member was very interested, particularly in recovery. This made me feel good. An email that I sent after the meeting to staff to follow up on recruitment of participants was met with an immediate reply to all from the head nurse, encouraging staff to help me in my research. I found this especially welcoming and supportive.

Interviews

21 June 2018 at 10:30 – Interview 1 with SUP1 at Hospital 2

My first interview was with a 30-year old female service user, diagnosed with bipolar mood disorder, who had years of experience with public mental health services. As it was my first interview, I was not sure at all what to expect from the interview and the participant. She told me that she is a physiotherapist. She was soft-spoken and compliant. She understood the research terms that I used, such as focus groups. Because she was well-spoken, she made the interview process easy and put me at ease. She seemed a little nervous at the start, but relaxed as the interview progressed. We talked about her becoming ill and how she coped with it and what recovery meant to her. I soon realised that she had a good support system at home and in the form of her psychologist at Hospital 2. I think this contributed to her progress with recovery. She was an out-patient at the stage of the interview. She focussed on her spirituality and the support of her family quite a lot. She mentioned her relationship troubles and stress at work that contributed to her mental illness. She emphasised the acknowledgement and coming to terms with or accepting the illness a lot. She used the word *contented* to describe how she felt at the end of the interview. She ended the interview by saying that she was not very keen to do the interview beforehand and that she was surprised that she was not anxious during the interview at all. I was glad about this. She recommended I speak to her sister, as a carer, without hesitation.

After the interview, I was grateful that this was my first interview experience for this study. It helped a lot in going into the next interviews. I felt like this was a good start to my research and a good participant to kick off the interviews with. I felt more relaxed and at ease after the interview.

5 July 2018 at 09:30 - Interview 2 with SUP2 at Hospital 2

My second interview was with a 35-year old male service user, diagnosed with schizophrenia. He was first admitted to Hospital 2 in August 2017. He was an in-patient (non-forensic) at the time of the interview. He was very respectful and soft-spoken. We conducted the interview in Afrikaans, which always makes me more comfortable, since it is my home language too. He seemed a bit nervous to start off with, but eased into the interview. He was very keen to take part in the research and share what he knew. With him I had to put in much more effort than the first interview to get him to contribute. I also found that he struggled to concentrate at times. After some time, he grew tired of answering questions. I tried to keep the interview as short as possible. I thought that perhaps he was either suffering side effects of the medication or symptoms of his illness. He told me that he wanted to get his life in order, to be able to start a family and so he was staying away from drugs. However, the week after the interview, his nurse told me that he had taken drugs the previous weekend out of hospital and so had to stay in the following weekend. I started to realise the social circumstances in communities that have such a great, sometimes negative, influence on the service user's recovery. The service users here all wear hospital uniforms, which is different to the civilian clothing that is allowed at the residential ward at Hospital 3. I wonder how that influences service users' perceptions of themselves and the hospital environment?

After the interview, although it was not as easy as the first interview, I felt satisfied. This was the first participant in which I could notice the effects of the medication or illness. I also had some insight into dysfunction in his home environment and noticed how it was important for him to let me know that his family cares. I wondered whether he would be able to find his way through the challenges in the community. I also realised, like I so often do

when I do interviews, that we are all human and want the same basic things, such as love, belonging, acceptance.

5 July 2018 at 11:00 - Interview 3 with SPP1 at Hospital 2

I went to the out-patient department building after my interview with SUP2, hoping to make an appointment with one of the psychologists for an interview at some point. To my surprise, a clinical psychologist was available immediately and we did a quick interview of approximately 35 minutes. She had put me in touch with my first participant. I was a bit nervous though, as I always am when interviewing staff. But, it was fine with her. I got the impression throughout the interview that she wanted to emphasise how difficult their working or community circumstances were. I felt somewhat pressured because of her time constraints, but I felt that it was better to make a start with the service provider interviews. She provided some good insight into the perspective of the service provider. She had worked in several divisions within the hospital, so she had a good understanding of the environment. The resource limitations came up as an aspect of her work environment. She highlighted the limited resources with which they must address systemic issues. Yet, she was still positive about the difference they do make in the lives of those service users that they are involved in.

I felt a bit rushed with this interview. It was a pity that we only had limited time to talk, she had another appointment soon after. She did offer that we could follow up with another interview, if I needed. After the interview, I felt like I could have asked her some more about the environment and the recovery work. After all my interviews were completed, when I had to arrange a focus group with the service providers at this hospital, I had to do it through this service provider and I realised that her continuing narrative, as it was during the interview, was that she is extremely busy and overworked. I realised this indicated the nature of environment in which the public mental health care takes place and wondered what this meant for recovery of service users.

6 July 2018 at 10:00 - Interview 4 with SUP3 at Hospital 3

SUP3 was a 29-year old male service user. I was looking forward to starting the interviews at this hospital, due to my very pleasant experience with the head nurse in setting up interviews at this hospital. SUP3 was a very keen participant. He was happy to jump right into the interview, but I had to explain that I must take time to explain the informed consent form to him first, but he just said *yes, yes* throughout my explanation. I had a suspicion that he was keen to please the occupational therapist at the hospital. He was diagnosed with bipolar mood disorder and to me it seemed to show in his interview. He tended to go into elaborate explanations, veer off topic easily, was very excitable, and spoke fast and a lot. At times, he spoke so much that he confused himself and lost his train of thought. He even sang to me later in the interview. I think he still suffered from residual symptoms; This made me feel somewhat nervous and anxious, because I struggle to get such participants *back on track* in the interview. He emphasised some of the issues I heard in the interview with SUP2 also. He struggled to concentrate fully and continually. Though he managed to speak quite elaborately, at times it sounded a bit rehearsed, as if he had made out some standard answers and thoughts for himself about his illness. He seemed to lose some energy towards the end of the interview. Sometimes I just let participants talk, because from my previous experience of doing interviews with public mental health service users, I know that they often don't have many outlets and derive satisfaction from having someone listen to them. This was what I did here.

I felt a bit disoriented after the interview. I felt exhausted from having to try and navigate the direction that the participant was taking and from concentrating intensely during the whole interview, yet I was grateful for the information that the participant shared.

10 July 2018 at 09:30 - Interview 5 with SPP2 at Hospital 2

My fifth interview was with a 58-year old female nurse. She had been working in the wards for 38 years and it was clear quickly that she had *seen it all*. Initially, she was very tense, serious and matter-of-fact. Her tenseness made me a bit nervous and I interviewed her in a very respectful way, as a younger person might do when speaking to an older person. Perhaps she thought initially that I would speak *down* to her, being from the university. However, I tried my best to bring across my genuine respect for her years of experience and knowledge. Right at the start she *corrected* my use of *recovery* as a term in an Afrikaans interview and translated it to *herstel,* the Afrikaans term for *recovery*. She warmed and relaxed as the interview progressed. She clearly had a wealth of experience and knowledge, as well as stories, to share. She focused a lot on what goes on in the community and the challenges that service users face when going (back) into the community. She lived in the community that the service users come from at the hospital, so she could give a good perception of the environmental challenges that service users faced. She came across as strict, but fair, with service users, which I think must be from years of having to set boundaries with service users and their families. She repeatedly emphasised a support system as the key to recovery for service users. A lot of the interview centred around taking medication and staying away from drugs. She also shared about families who do not want to take in the service users upon discharge and how this complicates the recovery for those service users. I realised once again the social circumstances in communities that affects service users' recovery so severely.

I felt satisfied about and good after this interview. She once again echoed some of the things that had been highlighted in the previous interviews too. I felt that I made a connection with her and she confirmed many of the thoughts about support that I already had before, in the context of recovery.

12 July 2018 at 09:30 – Interviews 6, 7 and 8 with SUP4, SUP5 and SUP6 at Hospital 3

I interviewed these three participants on the same day and in succession. In hindsight, it was a bit much to attempt all three consecutively. But, things worked out, because they were shorter interviews and not so information-rich as the other interviews. The nature of the interviews with these participants might be ascribed to the fact that they were in a long-term residential ward (non-forensic) and perhaps still experience many residual symptoms of their illness or side-effects of the medication or some form of institutionalisation.

I met with **SUP4** first, who was 35-years old and diagnosed with schizophrenia. He had spent 1 year in the ward, although he had been admitted several times, over many years, previously. He was very friendly and smiled a lot, but struggled to articulate, which caused me to ask him to repeat often. I sometimes struggle with hearing, especially in spaces where there is a lot of environmental noise, such as was in this ward. He seemed to struggle with side-effects of the medication; drooling, lack of concentration and struggling with his train of thought. I felt sorry for him. However, the more I listened to him (including afterwards when re-listening the interview), the more I realised my own biases in being confronted with someone who has a mental illness and displays residual symptoms or side-effects. In this case I missed some crucial contributions that he made during the interview, which I only picked up afterwards as I was re-listening the recording. This made me feel ashamed and I realised that I should listen to the participant more carefully and not be driven by my anxiety or need to come across as friendly. I was astounded at his contribution and very grateful that I had met him. Our interview lasted 45 minutes and towards the end I could see that he was growing tired. His concentration waned. He repeated the answers and my attempt to elicit a thicker description of aspects that he touched on just resulted in a circular conversation.

Next I went over to the adjacent ward to meet with the other two service users.

Here I first I met with **SUP5**, who was a 47-year old man, diagnosed with schizophrenia. He was very neat and precise. At first glance, he seemed out of place in this residential ward. He was well dressed, as opposed to some of the other service users in the ward, and well spoken. He spoke English very well, although it was not his home language and was more than prepared to do the interview in English. He was very friendly and smiled widely. He spoke softly, kindly and took time to give his answers. As the interview progressed, I realised that he had been in contact with a diverse group of persons from a young age, which perhaps made it easier for him to relate and speak to me. He did not display many residual symptoms or side-effects that I noticed, except perhaps that he was very quiet and withdrawn. I enjoyed speaking to him but got the impression that there was some pent-up frustration or anger that he perhaps struggled to express constructively. From what he shared, it was clear that he struggled with interpersonal relationships. Maybe this was due to the frustration or anger or from being in a psychiatric institution for 19 years and having limited ability to socialise generally. I felt sad about his situation at home, which was such that he was unable to leave the residential facility. His prospects for the future seemed dim. As the interview progressed the same pattern emerged as with SUP4 though: the circular conversations. I would ask what helps you, then he would say something. Then I would ask how does it help him, then he says it helps him. Quite frustrating for me, but understandable in his circumstances. As the interview progressed he also seemed to dislike some of my questions or perhaps he was just puzzled as to why I asked them. The institutionalisation showed in him. He seemed out of touch with the outside world and created the impression with me that he was only waiting for his house to be fixed to be discharged. It sounded like he did not receive visitors regularly. He was separated or divorced from his wife and he also could not give me a carer's contact details. He was very focused on doing the right things (participating with the staff and taking medication) to stay well.

My last of the three interview was with **SUP6**. She was a female service user, 38-years old, diagnosed with schizophrenia and had spent 2 years in the residential facility and seemed extremely quiet and withdrawn. She was timid, quiet and spoke softly. She spoke so softly that I had to ask her to speak up a bit, since I could not follow her at one point. She, however, struggled to raise her voice at all. She only answered what I asked and did not volunteer any information. She had experienced many hardships. She had been controlled by others in her life and seemed to have little agency. She seemed so sad. She was coherent when she answered and seemed to still be quite in touch with the outside world. She had an aunt who regularly phoned and sent money to her, but lives very far away in another province. The rest of her family (mother/bother) lived close by to the hospital, yet did not seem to take much interest in her. She spoke of one friend in the ward, but this also seemed like a tenuous relationship. I ended her interview earlier than I thought we would, because she seemed to struggle to engage further – she answered short answers and could give little additional information out of own initiative or after probes.

I felt very sad after her interview, and in fact after the three interviews in a row. I felt an immense amount of respect for these three participants, who seemed to keep going, despite their dire circumstances and prospects. These participants seem like the forgotten psychiatric patients that one reads about or hears of. I think their data might also not capture the richness of their experiences, because they often struggled to articulate and their attention span was affected, perhaps by medication, illnesses and institutionalisation. After their interviews, I decided to add a fifth interview to this group, to add more data.

13 July 2018 @ 11:00 – Interviews 9 and 10 with SUP7 and SPP3 at Hospital 3

I arrived a bit late, because of roadworks on the way, which made me feel unsettled going into the interviews.

I met with **SUP7** first. He was a 29-year old male service user, diagnosed with schizoaffective disorder. He had been in and out of hospital several times in the previous couple of years. He was very courteous, eager to take part in the research, well dressed and well spoken, although he struggled here and there to find the right word, but I tended to think it was rather a cognitive issue (perhaps brought on by medications) than a linguistic one. He said that he was comfortable doing the interview in English, although it was not his home language. He spoke enthusiastically. He was very positive in all his remarks. He seemed to take his mental illness, and recovery thereof, very seriously and came across as very responsible and acknowledged his role in his own recovery. At times, perhaps almost too convincing. He told me of stress at work that contributed to bringing on his mental illness. He also emphasised the importance of routine and positive habits, such as visiting his local library and doing exercise. It seemed as if he had listened well to the information sessions, where service users are educated on facilitators for their recovery. The one thing that stood out for me about him was his support system. He spoke of his sister and friends as his support system and relied on them for his recovery. He also emphasised the fact that receiving AND giving support helps him in his recovery process. I got the impression that he wanted me to see the good and positive and downplayed the negative or challenges, almost as if he needed to keep himself convinced too.

I left the interview wishing him all the best, and hoped that he would find his way again when he leaves the facility and had to navigate challenges of the community and the world. He seemed somehow vulnerable to me. I felt a sadness for him.

Next I interviewed **SPP3**, a 29-year old occupational therapist. She shared their ideas and innovations at the hospital, which seemed to be very focused on recovery and especially with attention to the individuality of the service users. This interview was one of the highlights of my interview process. She had a wealth of recovery information. She spoke

eloquently about the work they do with the service users. She had a good idea of what recovery is, at least the same way I look at it. The absolute highlight of my interview with her, was to hear about the narrative work that they do with the service users. They encourage service users to write their life story and then share it in the group sessions, if they feel comfortable enough. She told me of the changes, at least anecdotally, that they had seen in the service users through this work. Some service users even took the stories, that they had written down, home to share with family. This inspired me tremendously. Our interview was interrupted often and gave me an indication of the openness of her office to other staff and service users alike. She answered the interruptions during our interview each with no irritation at all. It seems as if the service users and staff relied on her very much. Her focus on storytelling is an exciting approach to recovery. She also liked my idea of bringing in service users who have been discharged and doing well as peer supporters.

I found the interview very informative. This was one of my longest interviews and, yet I was sorry that it had to end. I could have spoken to her for much longer. She was very positive without being unrealistic about the limitations of the environment in which she works. I felt very good after these two interviews. Both participants were eager to share and helpful. I gained a lot of insight from them both. The occupational therapist gave me renewed hope in public mental health services with her commitment and enthusiasm. She clearly went the extra mile for the service users in her care. The service user gave me hope for service users who are faced with severe challenges and manage to keep their hopes and plans for the future on track.

14 July 2018 at 09:45 - Interview 11 with CP1 from Hospital 2

It had been a long week up to this interview. I had already done six interviews the week and this would be my seventh. This female carer was 38-years old, the sister of my first service user participant and my first carer interview. She was pro-active in our arrangements

and I appreciated the care she took. She was there already when I arrived and we sat down at a quiet(-ish) table at the library she had suggested. Fortunately, the noise disturbance was minimal. I was excited to meet with her, since I had a very positive experience with her sister. I had a feeling that it would be a good interview. She was married with children and in addition, looked after or supported her sister, who lived with them. I experienced her as strong and not shy or scared to speak her mind. She was straightforward and direct, without being unkind. She was very articulate and well-spoken and had thought about the experience or implications of her sister's mental illness, so she could share quite easily. She provided a safe space for her sister. She challenged her sister to do things out of her comfort zone, to help her move forward, like finding work as a physiotherapist again, taking driving lessons and attending social events. She also referred to spirituality as an important facilitator to recovery.

I felt good after the interview, because it was a satisfying experience and the participant spoke easily and openly. This helped the interview process to flow. She gave me good and much insight into the carer's perspective, from a carer that is highly involved in the support of the service user. Many of the aspects that the participant touched on, were aspects that are known about the recovery process and the carer experience of it, so this served as confirmation for this context. I left feeling inspired by her energy and positivity and felt she could possibly inspire other carers.

17 July 2018 at 10:00 - Interview 12 with SPP4 at Hospital 3

SPP4 was a 28-year old male registered nurse, working in residential wards at Hospital 3. When we met before, he immediately impressed me with his professionalism and ability to articulate well, as well as seeming to be competent and having a can-do attitude. He has been very helpful in arranging my interviews and immediately agreed to participate in my research, when I asked him. He was one of the highlights of my interview process. He was

extremely committed to his work and the difference he can make in the lives of service users. He had agreed to participate in my research, but not only that, he came in to work on his day off to do this interview with me. Before I could start going through the informed consent form, he already started telling me about the history of the wards.

These wards were residential homes for patients with no homes to return to in the community. There were 68 patients housed in the two wards. He described the service users as clients and says that the relationship that staff (registered nurses, staff nurses and carers) have with the clients is more like family. The staff play a parenting role and the clients are siblings to each other. This is also the home of most of the clients and so they as staff deviate from the traditional roles of staff. I had some understanding for this, even though it sounded patronising. The service providers also don't wear normal nursing uniforms, to make it less formal and hospital-like. Building trust is an important cornerstone of the relationships for him with service users. We spoke about the institutionalisation that had set in for many of the clients. Some clients had lost hope, because they realised that they can no longer look forward to leaving, which makes them at times unable to be motivated to take part in some of the daily tasks, such as making beds, sweeping rooms, cleaning, washing. We also spoke about the gap that exists for those clients who get older and need a retirement home to move to. Often retirement homes are unwilling to take in psychiatric patients, even though they are stabilised and have been for years. That leaves staff at these wards with the challenge to care for elderly clients, which creates challenges because the elderly are not able to take part in and fulfil all the physical tasks in the wards, need help and then the younger clients are unable to understand that they are still required to fulfil their tasks when the elderly clients receive help. Hope was difficult to maintain for the long-term service users. He also kept close contact with each service user in his wards and did individual interviews with them to ascertain what they experience and need or require. This sounded out of the ordinary and

above and beyond the call of public mental health service duty to me. He said that the community health care workers (not family) have no psychiatric background and even the staff nurses are not trained in psychiatry. This places a lot of the burden of responsibility on him.

Although at times I felt that he spoke on about issues that might not be exactly relevant to my research, I left the interview feeling full of hope and happy, because he gave me a wealth of information to understand the context of the service users under his care. He gave me hope for a psychiatric population that are largely forgotten and side-lined. I felt optimistic about public mental health care. Afterwards I thought that I should put him in contact with another service provider at Hospital 2, who ran a recovery programme, perhaps he could also start something similar at the residential wards in Hospital 3. I went ahead and set up their meeting and both reacted positively. This is a very exciting prospect for me and a large part of the reason why I want to do this work. I want to connect people and facilitate co-operation and *cross-pollination* of initiatives.

25 July 2018 at 14:00 - Interview 13 with SPP5 at Hospital 1

SPP5 was a middle aged (he did not give me his age) psychiatrist with many years of experience in the mental health field and head of the service and my first participant at this hospital. The interviews at this hospital took very long to arrange. Although I sent numerous emails to staff, after my presentation there I did not get any response regarding service user participation or even staff participation for about a month. Perhaps this reflected the demanding work in public mental health services? I arrived at 14:00 at SPP5's office for the interview and he was not in his office. I already felt irritated, given my struggles to arrange the interview. I wondered how this would influence the interview and my perception of it? Fortunately, he arrived 20 minutes later. I am sure he had forgotten about the interview and it was a bit of a hassle for him. This made me feel uneasy. I also went into the interview feeling

very disappointed and hoping the interview would at least yield good data. He seemed calm, but somewhat distracted. I tried to elicit a thick description of his conceptualisation of recovery. Although he had no problem with being articulate, he often replied to my questions by saying that he was not quite sure of what I wanted. He used the word *whatever* quite a lot during the interview, especially when referring to an example of a patient situation. His answers seemed vague and distanced. I felt he was perhaps just tolerating me and that what they were doing in the public health service was the *real* work. He seemed cynical after years of working in this environment and I think his opinion of the service users was that service providers must help them achieve the best that they can, but that there is not much hope for them. His negative reaction towards my suggestion of peer support disappointed me terribly.

I did not feel that good after this interview. I felt like my work was idealistic and they were doing the difficult, real work. All the questions I asked were met with the challenges and limitations of the setting. I find that interesting. I wonder what the reason is? Perhaps also something in me? It felt at times there was a resignation in him, that was covered up by a neutrality or calmness.

30 July 2018 at 14:00 & 16:00 – Interview 14 with SUP8 at Hospital 2

SUP8 was a 23-year old female service user, diagnosed with schizophrenia. At first she seemed standoffish and quiet. She, however, soon started to tell me why she was in hospital - she had killed her brother. As she relaxed, she became keen to talk and explain recovery the way she understood it. She spoke about the recovery programme at this hospital (the first service user to do so!), so I was very excited to hear about it. She was very positive about the programme and her face lit up when I started asking her about it. She clearly got a lot of satisfaction and enjoyment from working in the programme. She tended to veer off the recovery topic and go back to her life story often during the interview. It seemed that the latter is what she wanted to talk about. Some questions that I asked, she did not have answers

for or she did not understand quite what I was getting at. She immediately referred to recovery as re-building connections in the community.

Although I was glad that I heard about the programme from her and her positive experience of it, I also felt a little confused and disappointed after the interview, because she struggled to express herself about recovery. Although, I spoke to SUP8 for more than an hour, I feel that I might not be able to use much information from her interview. But, perhaps the fact that she repeatedly referred to relationships, is in and of itself significant and underscores the need for support.

7 & 8 August 2018

Trying to organise carer interviews proved to be challenging. Thus far I had only managed to complete one carer interview. I was growing a bit wary of this process. Staff from Hospitals 2 and 3 reported that carers are either not involved or might have financial or logistical constraints that would prohibit them from attending an interview or they might just not arrive for the interview. I was waiting on several staff to let me know about interviews with carers. One service provider also let me know last minute, on 8 August, that my interview with another service user had to be cancelled for that afternoon, since the service user was uncontained at the time. This was a bit of a disappointment for me, because I was looking forward to finishing up my service user interviews at Hospital 2 that day and it contributed to my growing anxiety about getting all the interviews done in time. I was also confronted by the reality of working with persons with a mental illness; that the illness intervenes. I wondered how it felt for them, if it felt like *this* for me?

15 August 2018 at 10:00 - Interview 15 with SPP6 at Hospital 3

SPP6 was a 41-year old social worker at Hospital 3. I was keen to meet with her and hear her views on recovery, since she was my first social worker participant. While I was waiting for her, I saw two posters on the wall. The one poster was on recovery from Mike

Slade's team in the UK! I was very excited to see it up on the wall at this hospital. They seemed to have something of an understanding of recovery (at least as I also see it) here it! I liked SPP6 from the moment we met and I enjoyed the interview with her, because I could see she had a passion for the work that she was doing. While we were doing the interview in her office, her door opened more than once with service users wanting help with something. She was ever-patient. She was part of a larger team, of which I had interviewed two others already and their interviews were some of my highlights of the interviews so it was no surprise that I enjoyed the interview with her too. They had a good team and work going. She shared of her experiences of the service users and highlighted the challenges that service users and relatives face and the lack of resources in the public health sector and communities that makes these challenges so difficult. She spoke often about grant challenges and the interaction between families and the service user. A lot of psycho-education, and general education, of both service users and relatives or carers, takes place during her work.

I felt good after this interview. It was inspiring and hopeful to speak to someone who has such a passion for what she does. I was happy to have met her and I had a better understanding that it requires a group effort to run a service that seems to be somehow recovery-oriented. One person's idea is not enough, everyone on the team should buy into it. This is what they had here and I was glad for it. I felt, once again, inspired by their team.

17 August 2018 at 10:15 & 12:15 – Interviews 16 and 17 with SPP7 and SPP8 at Hospital 2

SPP7 was a clinical psychologist at Hospital 2 and worked specifically with forensic service users. He read through the ICF very carefully and brought up a lot of ethical issues, such as the storage of information on a laptop and the dangers thereof as well as the dangers of a cell phone being a target for robbers and being stolen with recordings on it. He took his time to sign it. I was somewhat taken aback, but I also knew that it was his right to ask

questions and I took the suggestions that he made as a constructive contribution and thanked him. This made me start the interview somewhat cautious. Once we started the interview, he soon warmed up a little and shared his passion for his work. He spoke a lot about service users' attitudes and how that was important in recovery. He spoke also about home visits by staff in remote locations and the positive experience of seeing a service user meeting up with close relatives after a long time. He explained how a leave of absence from the hospital and the process of admission of new service users works, which was very helpful. He said, when he started there, he needed to gain the trust of the service users and be patient with their process of getting used to him as a new service provider (staff turnover can be disconcerting for service users, who have to get used to a new service provider to share intimate or confidential details with). He also described how service users who go home and are positively affected by it gives them hope and works positively towards their recovery.

I left feeling surprised and good by the positive outcome of the interview, at the beginning being worried about his closed demeanour and being relieved by how he opened up and shared his passion.

I was very much looking forward to the next interview. I had heard about SPP8's recovery work for a long time, so I was excited to do the interview and found I had lots of energy to ask questions and try to understand. **SPP8** was a 54-year old occupational therapy technician, bubbly and full of energy. She was dressed informally, in a tracksuit and sport shoes, and spoke passionately about the programme she was involved in, how it all started and about the participants. She was clearly chuffed that the programme that she started 20 years before, was doing well. She spoke about many of the service users who had been or were (at the time of the interview) part of the programme. She knew everyone intimately and could tell me in detail how they had changed for the better through their involvement in the programme. What I also noticed was her calm demeanour. She had a silent strength about her

that I admired. She knew from the start where she wanted to go with the programme and I have no doubt that she would have found one way or another to get it to where it was. She was very in touch with each of the service users who were involved in the programme and watched them closely, if any one of them needed her guidance or support. She was something like a mother to the programme. She, however, did not elaborate on much else than this programme. She sometimes struggled to find the words to explain herself clearly.

I felt honoured to have met her and hear about her recovery work that was such a big success. Unassuming, yet a great force and admirable.

20 August 2018 at 11:00 - Interview 18 with CP2 at Hospital 3

CP2 was a 21-year old carer to her mother, who was in the residential ward at Hospital 3. She was also an engineering student at the time of the interview. Clearly, between the concern for her mother and studies, with a lot on her plate. She was a friendly, open person. I immediately felt glad to have met her. She had walked from the train station to the hospital where we met and said she was a bit nervous because she thought that some man had been following her. I realised again how using public transport makes one vulnerable in South Africa. She was carrying a heavy bag of books and a bag of groceries for her mom. She would visit her mom after our interview. I was surprised to learn, when we went inside the building to the nurse's office where we would do the interview, that she and the nurse had never met before. On her previous visits, he must have been off-duty every time. The nurse asked who her mom was and he immediately knew who her mom was. CP2 was articulate and friendly and a kind-natured, soft-spoken, caring young woman. She had last been to visit her mom about 4 months before, which I found strange because she seemed to care so much about her mom. I learnt that she was uncomfortable or felt it inappropriate to arrive to visit her mom empty-handed and she and her family (sister) could not always afford to bring something along. Also, travel was sometimes too expensive and so it, together with lack of a

gift or groceries for her mother, prohibited her from visiting. This made me realise the challenges in supporting in the context. I also found it interesting that she knew very little about her mother's current state of health, physical of mentally. As if it is not reported to her or she does not enquire? Perhaps the helplessness played a role in her not enquiring? She spoke easily, but with sadness about her mother. One of the main challenges for them as children, that she highlighted, was the loss of a mother; someone who could take in the role of mother and fulfil mother-type duties. She clearly felt a great loss. She also pointed out the lack of involvement of any other family members in her mother's life and that this saddened her terribly, but also made her angry at the other family. I felt sad, but could empathise with her feelings. She felt emotional almost throughout the entire interview. It also touched me emotionally to see her sadness. An issue she shared that I thought was of significance, was the fact that she had to step in for her mother, with her sister. Her sister needed someone to talk to about *mother-daughter things* and her mother was not able or available. So, she assumed this role. Another way in which the mental illness impacted on relationships of the service user.

After the interview, I felt huge admiration for the perseverance that this young woman showed in the face of such adversity. I felt satisfied after doing the interview and I think it produced such good data. Strange how others' sadness and adversity can make me feel satisfied about the data it yields?

20 August 2018 at 14:45 - Interview 19 with SUP9 at Hospital 2

SUP9 was a 34-year old female service user in a forensic ward. She was part of a recovery programme and I was glad I could interview her and get her impressions of her experience of the programme. She was friendly and spoke Afrikaans, my home language, however, some of the expressions and words that she used, I did not understand and it made this interview challenging. I felt uneasy, because of my not understanding what she was

trying to convey. I was scared I to miss some of the nuances. She also seemed to have an elaborate way of describing, using some images that did not make sense to me. I had to concentrate quite hard to repeat to her what I had heard, so that I could make sure I had the right understanding, it was a bit exhausting. She had a very concrete way of explaining and describing. Even when I had asked her to elaborate or explain. She spoke a lot about going home and her upcoming leave of absence (LoA), that she hoped would be for 3 months, one month longer than her previous LoA. She was very much looking forward to seeing her children and fiancée. She said that the programme was very good for her, but on the other hand she would rather work as a cleaner. I tried, but could not quite get what exactly was so much more attractive about a cleaning job than the programme. Her explanations were difficult to understand or were circular, so unfortunately not very helpful. What she earned for her work in the programme, she was saving up to have a birthday party for her children and herself, when she got home. She had, like many of the other service users, a certain lack of agency; they felt that they were without choice and their future dependant on the decisions of others. It was important for her to do what she could to get out of the hospital and back with her children and family.

I did not feel much of a connection with this participant. It was difficult to elicit data from her. I was wondering why the service providers were recommending me to speak to service users such as her and some others. What did they think would contribute to my research or what was I not seeing or eliciting? I felt a bit frustrated.

22 August 2018 at 10:00 - Interview 20 with CP3 at Hospital 3

CP3 was a 30-year old niece and carer for one of the residential service users. She was friendly from the moment we met and started talking immediately even before I could hand her the informed consent form. She spoke about her uncle and how long it had been since she visited him and how worried she was about him. She was emotional immediately

when she started telling me about her uncle and his situation. She shared easily and openly about her experiences as carer. She shared things that I was interested in knowing, so I felt very satisfied. She seemed to be an easy-going person and accommodating towards her uncle. After the interview, she met up with her uncle quickly and he was clearly very fond of her. She echoed some of the comments made by CP2, namely the challenges of being *the* family member who steps in and takes care of the service user. She also displayed a grasp of recovery that contained aspects like uniqueness, agency and empowerment. I was astounded! Social conditions were once again part of the issues that prevented her from taking care of her uncle better, as she put it. Guilt was something she carried with her and I tried to ease that by suggesting to her, the advice that SPP4 had given other relatives before (which he had told me the previous day) – the staff will take care of the service users, the relatives can visit, but if that is not possible (because of financial limitations, often) even a phone call every now and then would mean the world to them. She seemed to accept this suggestion.

She answered all my questions and it was one of the first interviews that I felt that the person was getting where I was going with my interest in recovery; even most of the staff did not get it. I felt like she could get involved in some way with caring for service users with the insight and compassion she displayed. I felt very satisfied after this interview. When she was leaving the ward afterwards, she was very pleased that she had seen her uncle and vowed to me to make more of an effort see or phone her uncle more often. I wondered how it would work out in the end? After the interview, I felt relieved that there were carers such as her, who took time to care for family members, even though it was not easy or convenient.

27 August 2018 at 10:00 - Interview 21 with CP4 at Hospital 2

CP4 was a 59-year old widowed carer with a son in a long-term ward. She was well dressed, friendly and polite and thanked me profusely for being *chosen* to take part in the interview. My first impression of her was that she was a proud woman. She began telling me

about her experiences with her son and the challenges that she had faced in her life. She ascribed much of the son's troubles to her late husband's abusive attitude towards them, his family. I realised, as we spoke, that it had taken her a long time, but she had finally taken a strong stand against what she experienced as abuse from her son (and late husband). Thereafter, I interpreted the initial pride as confidence and courage. She spoke a lot about her son's inability to take responsibility for his life and actions and her adamant position that he cannot live with her and her being judged for this decision, even by hospital staff. I learnt something of the hardships that carers, especially mothers, endure in the context of mental illness. I realised again that the mental illness not only impacts greatly on the individual service user, but on their family too. I perceived her as warm and kind, yet clear on her boundaries and that she was putting herself first, after years of being submissive and serving. She shared easily about her lifetime of experiences. I felt a deep respect for the experiences that she had as a carer.

It was a good interview and she shared a lot of information what is helpful for and added to my understanding. Some things that she said were like what others had said too and in that way confirmed some important facilitators and barriers to recovery. I left feeling a sense of pride for the journey that this carer had taken to get to this point and richer for having met her.

29 August 2018 at 14:30 - Interview 22 with CP5 from Hospital 3

CP5 was a 55-year old mother with a service user son, who lived with her and her husband at home, but had been in and out of Hospital 3 for many years. We conducted the interview at a school where she worked. She was lively and talkative and jumped right into the conversation, even before I had a chance to explain properly and ask her to sign the informed consent form. She continued for about 30 minutes before I could stop her and get the consent signed. This was once again an uncontrollable experience for me and made me

feel nervous. She started by explaining how music was one of her son's big loves. She also explained that she did not have much hope for his recovery and that he would always need care, because he was simply unable to perform most tasks for his day-to-day living by himself, like buying clothes and deciding that he had had enough to eat, or even eaten already. She told me about the challenges she faced within their family, because she often found herself in the middle between her son, on the one side, and the other children and her husband, on the other. She experienced her husband as giving little support when it comes to matters concerning their son. She tended to also talk about a certain topic and then get carried away with it and it then required great effort from me to bring her back, especially since I knew that we had limited time. This made me feel anxious and impacted my ability to guide the conversation. She painted a bleak picture of her son's prospects and future and seemed to be quite concerned about it. I sent her a contact number of a support group for carers afterwards, for this reason. She did emphasise the great support that her son experienced in their greater family, when her parents were still alive. He spent large amounts of time with them, and in their community. Stigma did not seem like an issue for them. We were under pressure to finish the interview, so I was not able to ask all the questions that I wanted to, but she still gave me some valuable data on her son and her experiences as a carer. There seems to be very little long-term support for her son in the community. I have great respect for the experiences and challenges that carers face and was once again reminded of this in the interview. I felt cheated a bit with regards to time, but I was satisfied with the information that she had shared and it linked with other carer's accounts, about which I felt satisfied.

30 August 2018 at 10:30 - Interview 23 with SUP10 at Hospital 1

SUP10 was a 35-year old service user, diagnosed with schizophrenia, and was friendly, timid, even nervous, when he entered the space for our interview. It was as if he was checking first whether I will be friendly to him. As the interview progressed, he became more

relaxed and very willing to share his experiences. It took me some time to get used to his accent - it sounded American, yet clear. It was easy to understand him, most of the time. He had little side-effects or residual symptoms from the medication or illness, except that he became a bit tired (yawned often) towards the end of our interview. I already was used to this by then and knew that the yawning signalled me to finish up the interview. He was very keen to take part and help me to understand what I wanted to know. He seemed determined to turn his life around and get a job and have a family. His circumstances, however, made me feel sad for him; I was not so sure if he would be able to fulfil his dreams. Having a family of his own, especially a son, was very important to him. He emphasised being independent quite a bit. He had been in the hospital for 8 years already and was keen to be discharged and live his life and dreams. His big goals were to get a job, get out of the hospital and being able to care for his daughter. Not being a burden was a major topic in the interview. He brought up the challenges of trust – being trusted by others in the community. I started to notice that I was hearing similar topics being raised by participants. This was a good sign - I was starting to reach data saturation. Only a few more interviews to confirm were necessary!

I requested a quiet, closed space, but we were given a glass-enclosed space and interrupted by a telephone in the space ringing repeatedly during the interview. This created quite a bit of stress for me; I struggled to hear and felt overwhelmed by the environmental over-stimulation. I tried to keep calm and accept the circumstances. I could see that the participant also became ever more impatient. Despite this, I was glad for the interview and hoped that he could realise his hopes for the future, but left the interview feeling sad about his circumstances. I felt irritated and angry by the disrespect for my research by the staff who arranged the interview location, given my struggle with this hospital from the start.

30 August 2018 at 13:00 - Interview 24 with SPP11 at Hospital 1

SPP11 was a 29-year old service user with a diagnosis of schizophrenia. I met with him in the ward and saw a notice had been placed on the door of the interview room in the ward that read, do not disturb. I was pleased about this, since it seemed to be towards the back of the building and quiet, and especially after my disruptive morning experience just before. He was less friendly than SPP10, yet still polite. He seemed a bit cagey about the interview and me and exactly what I wanted from him. It took some time to gain his trust through explaining myself and get him to open up and share some of his experiences. He told me about his art. His dream was to have a gallery and sell his art to earn a living. His parents had both passed away already and he only had an aunt, who was nervous of having him at home when she was not there, because of the things she feared he might get up to alone. He was admitted in 2015 as a forensic service user. He was very grateful to be in the hospital as opposed to a jail. He had also slept on the streets before. He also emphasised that importance of independence and taking care of himself (like SPP10). Saturation was nearing, I was hearing similar things over and over. He, like SPP10, wanted to have a family and children; he wanted his name to be carried forward. He was happy for me to talk to his aunt, about my research and her experiences with him. He seemed well-spoken and had the awareness that he had been of concern to a woman in a neighbourhood where he lived on the street and that she was instrumental in him being admitted to hospital for care. Unfortunately for him, she experienced him as too intrusive and got an interdict against him. I felt sorry for him when he told me that he would have liked her to see how well he was doing, but she was not willing to be involved further. It could also have been that he still did not understand the boundaries and did not respect them. I wondered whether he was trying to get sympathy from me or whether he was truthful. I still felt sadness for him. He wanted to belong somewhere and had

interpreted her concern as something more. I realised again that we all, at the core, have the same needs for love, belonging and support.

31 August 2018 at 13:00 - Interview 25 with CP6 at Hospital 3

CP6 was a 55-year old divorced mother of a service user son. We entered the space at the hospital for the interview and I was grateful that it was at the back of the building and quiet. She was very polite and friendly, but I noticed a sadness straight-away. When we sat down, I gave her the consent form, but she started talking about her struggles with her ex-husband and the work that she does immediately. She read through the consent form by herself and when I asked whether she had questions, she said no, it was all pretty simple and she understood it all. She agreed and she signed the form. She told me a lot about her son and that she worries about where he would stay when he is discharged from hospital soon after. She was unable to take him in, since she was staying with a friend herself, but he had no other support. Their circumstances seemed dire. She kept repeating that he needs a safe environment (closed place or institution) and that he would do well with supervision and routine. She worried that he would fall in with the wrong crowd again, since he was very impressionable and convinced easily by others. She worried terribly that her son would end up back in hospital, because of a non-conducive environment in the community. She felt that he was unable to live in the community safely and needed to be in a protected environment. She became very sad in the interview and broke down crying. When we ended the interview, she went to greet her son. They seemed very close.

I felt a great sadness for her situation, because I was not able to intervene. I realised that socio-economic circumstances played such a major role in recovery trajectories. Some service users were set-up for struggling by the lack of socio-economically sound environments that were conducive to recovery. I felt helpless.

5 September 2018 at 13:30 - Interview 26 with CP7 at Hospital 2

CP7 was a 22-year old son of service user parents. I did not know what to expect when I met him – I was not sure of how old he was. He had two older sisters. He immediately began to tell me about his parents. His mother was diagnosed with bipolar mood disorder, but seemed to cope better than his dad, who was diagnosed with schizophrenia. He struggled greatly with his parents' illnesses. He felt alone and isolated from his peers, they could not understand what he was experiencing and he had very few persons that he could talk to. I felt sad for him. He seemed a bit more mature than his peers might be. Yet, he was also enthusiastic and said that he was keen to take part in the interview. He seemed very intelligent, but I found he had some strange ideas about himself: he said that he was gifted and that his psychologist regarded him as a "modern day miracle", as he put it. It seemed like he tended to exaggerate a bit too. It made me wondered why he did that? I was wondering whether he struggled with some mental issues himself? I thought it might have perhaps been linked somehow to his mother's bipolar manic behaviour. But, I was not sure. I was just wondering and the thought came up. Towards the end of our interview, he had moments where he was incredibly emotional; upset and angry. I was concerned about him, checked with him whether we should stop, but he insisted that we could continue. At one point in the interview, he broke down completely and became angry and shouted about his utter frustration with his circumstances. He had to act as the parent to his father often (something that was an echo of CP2's views). He gave me some hair-raising examples of what he had had to endure over the years with his parents. After we finished the interview, I checked with him whether he wanted to inform his psychologist about the outburst, but he did not feel it necessary. He also said that he was an afterschool maths teacher to schoolchildren and that he thought I might think that he should not be working with children, given his family's history of mental illness. I understood it as the self-stigma that he experiences.

I felt very touched by this interview. It was the first I had done with a male carer. I suggested that he contact a support group for carers and perhaps go to one of their meetings. I felt intense sadness for him, but also shocked by his display of emotion during the interview. He, in fact, thanked me for the opportunity to get the emotions out afterwards. I wrote to his psychologist, whom I knew, and warned him of the experience, just to be sure. I did not hear for the psychologist again.

6 September 2018 at 14:00 - Interview 27 with SPP9 at Hospital 1

SPP9 was a 36-year old female occupational therapist and was also the person who arranged and chose the service users for me to interview at Hospital 1. It was an opportunity for some triangulation too. She was a delight for me to speak to, about her recovery-oriented work with the service users. She had a good idea of what recovery was (how I understood it) and she gave me many examples of how it was implemented in their ward. She jumped right in and spoke about all the aspects of recovery that I read about in the literature, like agency, empowerment, individuality, importance of own choice by service users, facilitating a process for service users, helping service users set goals, focus on not fixing, helping to cope or function (in her role as occupational therapist), finding purpose and meaning, hope and competency-building. She specifically emphasised the importance of service users own choice and came back to the point that each answer to the questions I was asking was related to individual service users' needs, preferences or choices. She referred to psychosocial rehabilitation (PSR) and the relationship with recovery and said PSR is about "living, learning, working, social". The phrase she used most often was, "Well, it depends on the service user." It meant that service users were being given the opportunity to make, at least some, decisions for themselves, within the limitations of the ward. She also suggested other service providers in the unit that I should interview and that one colleague introduced them to the Mental Health Recovery Star, which is very abstract (so difficult for some service users to

relate to), but helpful in looking at various aspects of recovery. I had very little opportunity to guide her in the interview, but in this case the data that came from it was useful, so it was fine. She spoke also about support to service users to achieve what they set out to do. She referred to the non-linear nature of the recovery process and the normalising of experiences (which made me think of the uniqueness vs normalisation of experiences). She also spoke about the need to build trust with service users and being authentic in dealing with service users. She used the word patients more, but apologised at the start for it and said she would use it interchangeably with service user. Interesting that at some of the hospitals staff refer to service users as clients and at others as patients.

I was very satisfied after this interview. She spoke about what I wanted to hear about recovery. The interview yielded many data and was very helpful to my work. I was very grateful to finally meet with her, after struggling for quite some time to set up the interview.

7 September 2018 at 15:00 - Interview 28 with SUP12 at Hospital 1

SUP12 was a 41-year old service user in long-term care at Hospital 1. He was a very interesting person to meet; full of energy and positivity. A lady who presumably also worked in the shop where he works on the hospital grounds came out to where I was waiting and said that I could go inside the building, SUP12 was waiting for me. He had obviously told others about the interview. I wondered what this meant? He is a tall, well-dressed man; very friendly and enthusiastic. He started telling me about himself and his experiences immediately as we sat down. He was used to speaking about his recovery experiences to others. It was good to hear, but I had to stop him to go through the informed consent form first. His English was difficult for me to follow during the interview. English being both our second language made it more complicated. I also felt it a pity, because I think I missed out on important aspects that he touched on that I could have explored more. I realised this afterwards, while listening to the recording. He did not always answer my questions directly

and this frustrated me a bit. However, he was so enthusiastic and determined about his recovery and what he understood about it, that it was difficult not to let him talk on about it. He was very adamant that recovery relied on the person (acknowledging that some support is necessary) and that the person needed to make the decision to move away from things that are harmful, like substances. He had very definite opinions about recovery and I got the idea that he was not open to other views, necessarily. Independence was of great importance to him too. He had been at the hospital for several years, since the early 2000s already. I wondered what kept him from being discharged, since he seemed to be doing very well in his recovery. Social circumstances?

I felt glad for the interview and his contribution and I was glad that he was in an environment that was conducive to his recovery and helped him to develop; work permanently and speaking about his experience to others. I felt a bit frustrated for not being able to stop him and get the questions that I wanted answered included in the conversation. I seem to struggle with that throughout the interviews.

8 September 2018 at 09:15 - Interview 29 with CP8 at Hospital 2

CP8 was a 55-year old female carer of her service user brother. She seemed to be quite familiar at the ward where we met; staff knew her too. This somehow put me at ease. I was glad for a nice, quiet space, the doctor's room in the ward and it seemed that a Saturday morning was quieter than in the week. She was soft-spoken and seemed to care well for her brother and support him. This participant seemed to do everything she could to support her brother in his recovery. She looked after his property in the community, brought him food and treats to the ward once, perhaps even more times, a week. They also seemed like a close-knit family, with another sister also being involved, however, a little less than the participant. She gave me insight into the process that a carer goes through when a family member is diagnosed with a mental illness. She had changed her approach to her brother and started

supporting him much more after the diagnosis. Meeting her gave me an alternative view on carer experiences, especially where no drugs were involved in the mental illness journey. Her brother had never taken drugs. It also gave me a view on a close-knit family, where parents were involved in the children's lives and how mental illness can play out in those circumstances. This was very much like my interview with SUP1 and her sister, CP1. Support and love were the two things that she highlighted as most important to recovery. Of all the families (except perhaps SUP1's), this family seemed to be the most closely knit and functional.

I enjoyed the interview probably the most of all my interviews, because she was straight to the point and clearly answered my questions. I was satisfied after the interview. I felt glad to also have her perspective. She was emotional at times, but seemed to be able to deal with the emotions quite well. She made me feel comfortable, although in hindsight I am not sure whether my comfort was paramount. It also signified the point where I had finished my interviews at Hospital 2 and I felt a sense of accomplishment. It felt good.

12 September 2018 at 11:00 - Interview 30 with SPP10 at Hospital 3

SPP10 was a 47-year old female psychiatrist at Hospital with 20+ years of experience in the field. I was nervous leading up to the interview - over email she sounded curt and matter-of-fact and the possibility existed that she was just granting me the interview because I was not getting an interview with her junior colleague, who was uncomfortable taking part because of his perception of his inexperience. She was very friendly and inviting and we went straight to her office. She signed the informed consent form immediately, having gone through it already in the past. We started the interview immediately and I was very aware of how busy she was. Although this put me under time-pressure, she put me at ease with her friendly, yet direct way. She seemed keen to share and we conducted the interview in Afrikaans, which put me at ease even more. She mentioned that Hospital 3 is a bit different

than Hospitals 1 and 2. She prided herself on the fact that new rules and regulations got implemented there mostly before it did at the other two hospitals. The management of the hospital apparently run a tight ship - I wondered what this meant? She was a matter-of-fact, energised person, who was a realist and seemed to have *seen it all*, something that I found with quite a few of the service providers. Perhaps somewhat disillusioned already by the limitations of the public health care system? She kept coming back to the fact that some service users can be helped and others not. She emphasised the fact that medicine (psychiatry) could only do so much and then not more. Then it was up to the family or support structures to take it further. "Be the best possible you that *you* can be" was her opening phrase when starting to talk about mental health recovery. Within acute care the idea is to get people through the system. With chronic care it seemed more complicated because it requires time and time is a luxury in a public health care setting. She emphasised that an individualistic approach is what is ultimately needed to attend to psychiatric illness properly. She answered my questions very directly and precisely, which helped. It seems to give me more energy and want to delve deeper into the interview. What was interesting was that she mentioned a few times that service users must not make the same "mistakes" (as she called it) over and over - it seems as if she perhaps regarded the *problem* as located within the person. I had heard this type of thinking from several psychiatrists before. It might be because of the population and the overwhelming need for help that they face? She did refer to aspects such as support, even just one supporting person, and routine as crucial to recovery. She also referred to faith as a great means of support.

I felt satisfied after meeting with her. I think she made a valuable contribution to my data. She made me feel more at ease in her company than the other psychiatrist that I interviewed and I was glad that I had interviewed her.

12 September 2018 at 14:00 - Interview 31 with CP9 from Hospital 1

CP9 was a male carer of his service user brother. The house where we met was the house in which the carer and his brother, the service user, had grown up and it belonged to their parents before. He had been living with his brother since the end of 2017, so it was all still a bit of a new experience for them. His brother was not there at the time of the interview and I was relieved. Before this arrangement, his brother had been admitted to Hospital 1, and before that he stayed at a halfway house. I had heard about halfway house before from CP6 and it did not sound good, so I was wondering why the mother had placed his brother there before her death? CP9 was very enthusiastic about our interview. He was a well-spoken, open man, who clearly had made peace with his brother's condition, cared for him a lot, and shared much of his experiences with his brother. He was not his brother's first carer, but since their parents had passed away, it fell to him to take care of his brother. It took him some time to get to the point of having his brother stay with him and my impression was that he took it one step at a time with his brother. He was open about his inexperience and open to learn. He was involved in his brother's life, but also not overly so. It seemed they had a healthy relationship. It also seemed that he let the relationship and recovery process with his brother develop or unfold as time went on. He did not have pre-conceived ideas about how it was supposed to work, I thought this was a positive aspect of their experience. He and his wife seem to provide his brother with a stable, loving and accepting environment. It is not many relatives who are prepared to do this. I am sure it helped his brother in feeling a sense of belonging. He also said that a service user needs to come home to feel that sense of belonging and to recover. He seemed, though, like he could do with some help in understanding his brother's illness better.

I felt good after this interview, being able to once again see what family do when they can care and provide. It seems the interview provided some insights for the participant too. I

felt grateful to have met him and to hear about his journey with his brother, which seemed so unaffected by pre-conceived ideas that it was actually refreshing.

13 September 2018 at 14:00 - Interview 32 with SUP13 at Hospital 1

SUP13 was a 44-year old male service user at Hospital 1 and was identified by the occupational therapist for me to interview. At first, he was not sure what this would be about. He seemed a bit dishevelled. He soon settled and I explained the research to him. He kept focussing on when I would be coming back again. I kept saying the next year in February or March. He was very soft-spoken, in fact so much so that I struggled to hear him at times and had to ask him to speak up. He also kept fidgeting with the paper in his hand, so much so that I worried that that recording might not be good for transcription. I asked him to speak up, but it did not help. He answered many of the questions with a "I don't know". This made the interview very short, one of the shortest. He focussed quite often on communication and on having others or friends to talk to. He said that he did not experience any stigma or prejudice about his illness and no relationships with family or friends was affected by the illness. I was not sure if I could believe him, though. He had spent 7 or more years in this hospital. He also said that he was waiting on his sister to decide whether he is better and can come home - he visited her every second weekend. He managed to tell me that the two days a week, that he works, is his favourite thing to do, because he gets to talk with people. He was not able to go into details or tell me why he gave the answers that he did. He could also not give examples from his life. He gave me very little information and sadly made little contribution to the conversation. He mostly answered yes or no to questions.

I felt frustrated after the interview, because I would have to transcribe it myself, since he gestured many answers and the recording might be very faint. I felt disappointed, but also understood that this was a type of experience that is part of interviewing service users in these circumstances..

14 September 2018 at 14:00 - Interview 33 with CP10 from Hospital 1

I was ill with a cold, but did not want to lose the interview and so I persevered. I was a bit nervous about the location of the interview, because it was a dangerous neighbourhood. Fortunately, I managed to safely arrive at CP10's home.

CP10 was a 61-year old carer mother of one of the service users whom I had also interviewed. I looked forward to this interview, because it would allow me to understand the same service user's situation from more than one perspective. She seemed in her own world, singing in her lounge, but with the door open and security gate locked. I managed to draw her attention and she did not seem sure of who I was at first or what I wanted, which seemed strange, since we had an appointment. When I introduced myself, however, she immediately changed her serious demeanour and became friendly. She invited me in and we sat down in her lounge. I explained my research to her and that I was not part of the hospital, so anything she said would stay confidential. This seemed to put her at ease. She was polite and contributed what she could, but I experienced her as extremely sad about the situation with her son and feeling helpless - he could not come home, because of the bad influences in the neighbourhood where they lived and she was desperately looking for an alternative place for him, outside of the hospital. She emphasised that her son did not have resistance to peer pressure in the community and that the environment in which they lived was not conducive to his recovery. Yet, she also felt that when he was healthy, by which she meant taking medication and stabilised, he was "normal" and did not belong in hospital with all the "sick people" there. She expressed uncertainty about recovery for her son. She kept saying that she needed him at home, but that the environment was bad for him. I could see that it created a great conflict for her. She said a type of rehabilitation centre would be ideal, but said she was unable to locate one. I realised the lack of resources in communities again.

I felt deeply sad for her when I left the interview, but also grateful that I could speak to her and understand more about her challenges in the recovery process. I was also glad that we conducted the interview in her home environment, it gave me a better understanding of the challenges there. Her sadness affected me and made me feel her hopelessness for quite some time after the interview.

19 September 2018 at 10:30 - Interview 34 with CP11 at Hospital 1

CP11 was a 77-year old widowed female carer mother with a son as a service user. She was due to have a serious operation and almost had to cancel the interview. I was very relieved when we could fix the time and date, since I had been struggling to get all the interviews done at this hospital and felt frustrated and like giving up at times. She had been a nursing sister for 54 years. Her focus was on the importance of religion and that her son would never recover fully. She was worried about him, because she was 77 years old already, and her son was not able to properly look after himself. She said that she wished a job, wife and family for him, but that these things had not materialised yet. She also felt financially constrained and that this exacerbated her worry about her son's future, that she would not be able to financially care for him adequately after her death. She also highlighted her struggle in managing her son – she sometimes found him challenging and disruptive and this added to her anxiety about his future. She was also rather critical of the hospital. She said that he had experienced things that were very detrimental to his mental health in the process and that some practices in wards were very demeaning. She implied that he did not belong in the hospital. She was one of the only participants that articulated the fact that the hospitalisation caused her son severe trauma (and might even perhaps have caused him more damage than the illness). Although the prospects seemed bleak for them, I came to a deeper understanding of all the challenges that families, in which mental illness occur, face.

I felt a deep sadness for them and thought of them often afterwards. I was appreciative of this interview, although it was sad to see the struggle that she had with her son's mental illness. She presented a bit of a different perspective than some of the other carers that I had interviewed. I found this to be good, being a diverse perspective. The hopelessness and desperateness of her situation touched me. Her interview, together with the previous carer's interview, made me realise again the huge struggles for persons at the intersection of poverty and mental illness.

19 September 2018 at 13:15 - Interview 35 with SPP11 at Hospital 1

SPP11 was a female clinical psychologist with a particular interest in recovery. This interview was the most difficult to arrange. I sent email upon email and even tried calling and asked around when I visited the hospital. I struggled to get any response from her at all. And then, when I was already making plans to interview other service providers at the hospital, she responded. After my previous interview, I tried to call her, but could not get hold of her. I then did some things before planning to head off home again. I suddenly received an SMS from her saying that I could see her in one of the wards. I was overjoyed! She would be helpful for me in gaining an understanding of recovery in this context from a more professional perspective. She started talking almost right away, but I stopped her so we could complete the informed consent form first. I realised that I was quite nervous about interviewing her. I think my nervousness came from the fact that she is *the* recovery person, according to many other colleagues of hers, at this hospital and she would *know* if I did not know what I was talking about. She seemed distracted and somewhat disinterested in the interview initially. However, as the interview progressed, it seemed that she found some interest in the work that I was doing. She spoke about recovery in the forensic context. She said she used the term secure recovery and that recovery was limited by this context. After a while I ventured an opinion that one could refer to *protected recovery*. This term seemed to

impress her and she said something about getting a different perspective from others. I felt good about that; that I had could perhaps add something to her understanding of recovery too.

After the interview, I felt satisfied that I only had two interviews left to do, of which one was already organised. I was satisfied with the result of the interview and glad that I could contribute to her understanding too.

24 September 2018 at 11:00 - Interview 36 with CP12 at Hospital 1

CP12 was a female aunt carer of a nephew service user in long-term care. She was a beautiful woman, well-dressed and quiet. We went to the ward and went inside for the interview. Her nephew was not in the ward. She seemed nervous, especially when someone walked past the window. I asked her about it and she asked whether we were safe in the ward. I tried to re-assure her by saying that I had been there a couple of times and had never had a situation where I felt unsafe. It seemed to re-assure her a bit, but not much. She was concerned about the time we had to do the interview, because the person who had brought her by car had to return at a certain time. Initially she said she only had 10 minutes for the interview, but we managed to speak for about 35 minutes in the end. I think doing the interview in a second language, English, made it difficult for her. Although her understanding of English was good, I think she did struggle to express herself and find the words to describe experiences. I tried to help with words where I got the idea of what she was trying to say, but without prompting her too much. She kept returning to her opinion that the drugs were the root of her nephew's problems and that she feared her nephew when he was at home with her. She began crying when she said this to me. I could feel the sadness.

I felt a bit disappointed by this interview. Although I was very grateful, I felt a bit short changed by her answers that were extremely short and not very descriptive. I had the feeling that she felt rushed. I remembered that, it is what it is.

24 September 2018 at 12:30 - Interview 37 with SPP12 at Hospital 1

SPP12 was a 64-year old male nurse. I was relieved that we could have the interview in relative peace and quiet in a private room in the ward. I explained that I had been referred to him by other service providers and explained my research. He expressed his concern about me perhaps being a journalist and I had to assure him by showing him the approval letter from the Department of Health. This seemed to satisfy him and he was happy to sign the informed consent form. We conducted the interview in our mutual home language, Afrikaans. He was a seasoned nurse and had worked in forensic wards and the wider hospital for more than 40 years. We started the interview and he immediately said that recovery is when someone can return to the community from the hospital and not be re-admitted thereafter. That was the indication that recovery had been achieved 100%, according to him. He kept returning to this statement throughout the interview. He emphasised the role of community in recovery, which was an interesting, and important, perspective that not many of the other participants had. We spoke quite a bit about the role of stigma too. He also mentioned the rights of patients that had come more to the fore in recent years. Although he agreed that it was important and not to be dismissed, he also said that this posed some challenges for them when patients insisted on exercising these rights despite being seriously ill and needing care.

I was so pleasantly surprised by this final interview. I enjoyed this interview and pleased that this interview was my last. He seemed to warm to me as the interview progressed and I am always grateful when this happens. I found it fascinating to experience a slice of mental health care through his years of extensive experience.

I felt that I had managed to get a diverse or broad-ranging number of participants and their insights through the interviews. This was exactly what I hoped for.

Focus group discussions

Initially, I had planned to do nine focus groups: one for each participant group at each hospital. However, after deliberation with my supervisor and given the struggles I had with organising the interviews, she suggested that I only do one focus group for each of the participant groups. I had transcribed some of the interview recordings myself (the others were done by a transcriber) and provisionally analysed the data from the interviews between October 2018 and January 2019. I started arranging the focus groups and thought that I would start with the service users from Hospital 1. The reason for this is, because I thought it would probably be the easiest to arrange. I had never facilitated a focus group before and was somewhat unsure about it. I asked a Master's graduate in psychology to join me in the focus groups as an assistant. She kept notes during the focus group and would prove useful as a sounding board afterwards by us talking through what had happened during the focus group. Although I meant to use the focus group interview guide (drafted much earlier) as a guide, in the end the results of the interviews were the main focus of the focus groups. However, the guide still reminded me to keep to the same topics as in the interviews, to validate them.

2019-03-27 at 15:30 - Focus group 1 with service users at Hospital 1

SUP9, SUP10, SUP13 and a new participant, SUP14, participated in the service user focus group, i.e. focus group 1. SUP14 was a 31-year old service user, with a diagnosis of schizoaffective disorder, bipolar type.

My research assistant and I arrived very early and waited outside the ward in the car. This proved to be a bit of a challenge, because many service users came to check what we were doing there, chat to us about all kinds of things and poking and prodding as to why we were there and whether we could offer them something. Finally, it came closer to the time for the focus group and we moved inside. The focus group was at 15:30 and this was a busy time with many of the service users being outside the ward building. The space we were given was

on the opposite side of where I had conducted interviews before and I was pleased about it. I thought it might be quieter than the other side of the ward and it proved to be. The participants signed the informed consent forms, I gave each the summary of the results from the interviews. I explained the results, but perhaps in my opinion in hind sight, a bit too much. SUP14 seemed to fit in quickly with the others and contributed equally, if not more, than the others. SUP11 also contributed a lot to the discussion. SUP9 contributed a fair amount at the start, but started struggling later – he started speaking by himself when others were speaking and repeated a lot of what other were saying to himself. SUP13 quickly indicated, in the first round in which I gave each an opportunity to say something, that he would not be saying anything during the focus group. This made me wonder why he was there? I was a bit frustrated by this. I was, however, pleasantly surprised by the contributions that SUP14 and SUP11 made. I struggled to understand why SUP14 was still in the ward and had not been discharged yet, but learnt that he had a difficult time being accepted back home, because of the behaviour that landed him up in the hospital.

Through this focus group, I was once again reminded of the difficult and, at times, appalling circumstances that the service users in public mental health facilities find themselves in. I understand that all that can be done with the limited resources to their disposal is done by mental health service providers, but still I could not imagine that the circumstances in these dilapidated wards are conducive to recovery, except perhaps for the most resilient. Service users are, as all of us are, vulnerable to their circumstances or environment - how could they recover in these wards? I also thought of the nurses and workers in the wards, who were at the coalface of interactions and in a way lived in these circumstances too – how did it affect their service delivery and their hope for these service users?

2019-04-13 at 10:00 - Focus group 2 with carers at Hospital 3

The focus group for carers at Hospital 3 proved to be more difficult to arrange that I had initially anticipated. A few days before the first date, the one carer (of four) had to cancel. I was disappointed, but I was confident that we could continue with three anyway. Then, the night before the focus group, a second carer had to cancel. I was disappointed and a little upset because she had told me so late, but she had a valid reason. I had time constraints - I needed to get the focus groups done to have them transcribed, the data analysed and move on to the next step in the research process. Some of the others then indicated that they would be able to attend two weeks after the previous date. I hope that a third carer could make it and when she indicated that she could and I was very pleased. In the end, it was just three participants, because again the fourth carer could not make it. I proceeded in order to get it done.

The atmosphere for this focus group as completely different to the one with the service users. There was CP2, who was a student in electrical engineering and daughter of a female residential service user, CP5, a mother of a male service user who was living at home with her, and CP3, a niece who had a service user uncle in the same residential ward as CP2's mother. When the focus group started, I could not get the carers to stop talking. Especially CP5. She tended to take over the conversation, even though I had laid down the ground rules at the start (not to interrupt others or speak over them, and so on). It irritated me a bit, because CP5 took it upon herself to be concerned about CP2's situation and identify with CP2's mother. I found it a little inappropriate, but CP2 took comfort in the concern by CP5, so I let it be. I think CP2 somehow appreciated the mothering that she was missing from her own mother. CP5 vowed to keep contact with CP2 and visit her mother in the ward. CP3 brought her young baby along to the focus group and this created a challenge in terms of noise and distraction for her. The baby was crying and fussing a lot and one picked this up on

the recording. Fortunately, not much was lost from what participants were saying. They all emphasised the challenges that carers faced and each from their perspective. They were all the ones in their families who took the responsibility for their service user and found this a challenge, since other family members either did not want anything to do with the service user or very much welcomed the participants taking responsibility for the service user, so that they as family members did not have to take that responsibility. This placed an enormous burden on these carers, which they elaborated on. They also expressed their gratitude for the opportunity to share with each other in a group about their experiences and said that there were too little opportunities for them to do so otherwise and would welcome a support group.

I left feeling immense respect for the role they played, despite their financial constraints, in the service users' lives. I had no idea what big task this was and only got a glimpse of it in the focus group. I was glad for the focus group, but not sure how much of the data would be useful in the end for my research purposes.

2019-05-14 at 09:15 - Focus group 3 with service providers at Hospital 2

In the end, this focus group with service providers proved the most challenging to organise. I think it was because of the demands on their time as service providers. It perhaps is also an indication of how thinly spread the service providers are in public mental health care. It took three dates (2019-04-10 at 13:30; 2019-05-02 at 10:45) before I could get (only) three service provider participants together for this focus group. Each time there were too little participants and I was very disappointed and felt like I had failed the others that did arrive in some way. I felt as if I could have done more to get a third participant there. But, there wasn't. Fortunately, third time did indeed prove to be lucky and we had three participants; SPP1, a clinical psychologist, SPP8, an occupational therapy technician, and SPP2, a nurse. I was disappointed that one of the psychiatrists could not make any of the three dates, but, in the end, it was also probably better that way. It might have injected an

uneven power dynamic to have a senior service provider (psychiatrist) in the group. SPP1 was the person that I arranged the focus group through and she made me acutely aware of how busy and under pressure she was. So, by the time the second date needed to be arranged, I, contrary to my nature of not taking over things when it is not my place, took over the arrangements from her. I think she was grateful to not be further burdened by the responsibility of this. SPP1 arrived first for the focus group and thereafter SPP8, who apologised for missing the previous date as they were short-staffed, SPP2 arrived last. I panicked for a moment before SPP2 arrived, worrying that she would not. I had phoned her and reminded her the day before, so I was confident that she would keep the appointment, since my impression of her was of someone that kept to what they had committed to, but I still had a bit of doubt. We had limited time, since the participants all had appointments afterwards to get to. So, we had to move through the results quickly. This has a benefit in focusing the group and making them get to the point, but can also make one miss some of the finer nuances and things participants would have said, given more time. Fortunately, with all the previous scheduled focus groups that did not work out, I had most of the informed consent already signed and only had to ask SPP2 to sign. Interestingly, I felt compelled each time to call SPP2 by her title and not by her first name, like all the other participants. Somehow her demeanour and strict way demanded the respectful address. SPP1, I think because of running group therapy sessions regularly, took over the managing of the focus group a bit and I let her. She often said, “I hear what you say…” to the other participants. This is something that I can imagine she said in the group therapy sessions to service users. My impression of SPP8 was that of a loving, warm and kind person. Each of the participants spoke about (and in a way repeated) what they emphasised in the interviews – SPP2 about support, adherence to medication and independence, SPP1 about acceptance and overburdened staff and SPP8 about the recovery programme she was part of, independence

and collaboration. Perhaps a fourth participant might have brought something else to the group and had them discuss more varying aspects of recovery? A very exciting thing happened during the focus group: SPP8 indicated, and SPP1 realised, that the recovery programme at their hospital was not just for in-patient service users. I noticed immediately that SPP1 was seeing possibilities of perhaps sending some of the service users from the out-patient division to take part in the programme. The possibility of this connection excited me, like with SPP4 before. We moved quickly through the themes for recovery, the facilitators and the barriers.

I would have liked to have had more time to discuss in detail. I am glad to have ended the focus groups with the service providers. A good experience for me of the demands on their time and energy.

Cognitive Interviews

2020-02-14 – Cognitive interview 1 with SUP14 at Hospital 1

This service user was the additional service user that I recruited for the focus group, because I did not have enough participants from the interviews to conduct the focus group. This was my first cognitive interview and I had done much preparation for it. I felt somehow proud of the process that had brought me to the point where I could present the measure, albeit a draft version, to a service user. I enjoyed the process of going through the measure with the service user and he gave me such valuable insight into his process of understanding the measure, that I felt very grateful to him afterwards.

2020-02-14 – Cognitive interview 2 with SUP11 at Hospital 1

I conducted this cognitive interview on the same day, but in the afternoon with one of the service users who participated in an interview, a focus group and now a cognitive interview. I felt like he was becoming one of my trusted advisors in the process of developing the measure! I felt a connection with this participant and was so glad that he was available to

contribute to the measure in a tangible way, such as this cognitive interview. He provided a valuable contribution to my understanding of how he understood the measure. Since this was our third engagement, I felt we had a strong rapport and my experience was that he could express ever more openly, which was very helpful. He was not afraid to tell me those instances where the measure or items did not work and made some very helpful suggestions for changes.

I felt very grateful for the two contributions I received from SUP11 and SUP14 this day. I hope the measure would ultimately be something that could help them, in particular, in future.

2020-02-17 – Cognitive interview 3 and 4 with SUP5 and SUP4, respectively, at Hospital 3

A few days after the first cognitive interviews, I conducted the other two cognitive interviews at one of the other hospitals. Admittedly, these two interviews were a bit more challenging than the first two. But, I anticipated this going in and prepared for it by knowing to be patient with the process. I relied on cues with these participants a bit more than with the previous two participants and did not go in to all the details, if an item was similar to a previous one or an issue had been raised already. I had to lead these two participants a bit more with probes to elicit their responses. Both participants gave me additional feedback that helped me to refine the items and measure further and I was so grateful for that. It was satisfying to see the measure developing with their input.

I interviewed the two participants one after the other and it was quite tiring, but I was glad that I could complete this part of the content validity process so smoothly and, seemingly, successfully.

Appendix C6: Questionnaire about the Process of Recovery

The Questionnaire about the Process of Recovery (QPR)

[15/10/2007- Version 1]
[02.04.2014 Version 2]

We developed this questionnaire in order to understand more about the process of recovery; what's helpful and what's not so helpful. Everyone is different and there will be differences for everyone. The items on this questionnaire were developed through a process of interviewing service users about their recovery journeys. We hope that by filing in this questionnaire you will help us find out information that is important to you and your own recovery. Not all factors will be important to you, since everyone is different. This questionnaire is not intended to be used to impose anything against your wishes.

If you would like to fill in the questionnaire, please take a moment to consider and sum up how things stand for you at the present time, in particular over the last 7 days, with regards to your mental health and recovery. Please respond to the following statements by putting a tick in the box which best describes your experience.

		Disagree strongly	Disagree	Neither agree nor disagree	Agree	Agree Strongly
1.	I feel better about myself					
2.	I feel able to take chances in life					
3.	I am able to develop positive relationships with other people					
4.	I feel part of society rather than isolated					
5.	I am able to assert myself					
6.	I feel that my life has a purpose					
7.	My experiences have changed me for the better					
8.	I have been able to come to terms with things that have happened to me in the past and move on with my life					
9.	I am basically strongly motivated to get better					
10.	I can recognise the positive things I have done					
11.	I am able to understand myself better					
12.	I can take charge of my life					
13.	I can actively engage with life					
14.	I can take control of aspects of my life					
15.	I can find the time to do the things I enjoy					

Thank you for completing this questionnaire

Appendix C7: Maryland Assessment of Recovery Scale

Maryland Assessment of Recovery Scale

This scale contains a list of statements about your attitudes and beliefs about your health and wellness. There are no right or wrong answers; we just want to know what you think about these things. Read each statement and then decide how much you agree with it, from **Not at All** to **Very Much**. Then circle the number that best reflects how much you agree with each statement using the following scale:

Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
1	2	3	4	5

	How much do you agree with the statement?				
	Not at All	A Little Bit	Somewhat	Quite a Bit	Very Much
1. I can influence important issues in my life.	1	2	3	4	5
2. I have abilities that can help me reach my goals	1	2	3	4	5
3. I believe that getting better is possible.	1	2	3	4	5
4. When I have a relapse, I am sure that I can get back on track.	1	2	3	4	5
5. I have skills that help me to be successful.	1	2	3	4	5
6. My strengths are more important than my weaknesses.	1	2	3	4	5
7. Overcoming challenges helps me to learn and grow.	1	2	3	4	5
8. I can have a fulfilling and satisfying life.	1	2	3	4	5
9. It is up to me to set my own goals.	1	2	3	4	5
10. I believe I make good choices in my life.	1	2	3	4	5

	How much do you agree with the statement?				
	Not at All	**A Little Bit**	**Somewhat**	**Quite a Bit**	**Very Much**
11. I am responsible for making changes in my life.	1	2	3	4	5
12. I feel good about myself even when others look down on my illness.	1	2	3	4	5
13. I am confident that I can make positive changes in my life.	1	2	3	4	5
14. I am responsible for taking care of my physical health.	1	2	3	4	5
15. I work hard to find ways to cope with problems in my life.	1	2	3	4	5
16. I believe that I am a strong person.	1	2	3	4	5
17. I am hopeful about the future.	1	2	3	4	5
18. I feel loved.	1	2	3	4	5
19. I usually know what is best for me.	1	2	3	4	5
20. I know that I can make changes in my life even though I have a mental illness.	1	2	3	4	5
21. I am able to set my own goals in life.	1	2	3	4	5
22. I am optimistic that I can solve problems that I will face in the future.	1	2	3	4	5
23. I can bounce back from my problems.	1	2	3	4	5
24. I feel accepted as who I am.	1	2	3	4	5
25. I want to make choices for myself, even if I sometimes make mistakes.	1	2	3	4	5

Appendix C8: Recovery Assessment Scale

RECOVERY ASSESSMENT SCALE

Date:_____

INSTRUCTIONS: Below is a list of statements that describe how people sometimes feel about themselves and their lives. Please read each one carefully and circle the number to the right that best describes the extent to which you agree or disagree with the statement. Circle only one number for each statement and do not skip any items.

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
1. I have a desire to succeed.	1	2	3	4	5
2. I have my own plan for how to stay or become well.	1	2	3	4	5
3. I have goals in life that I want to reach.	1	2	3	4	5
4. I believe I can meet my current personal goals.	1	2	3	4	5
5. I have a purpose in life.	1	2	3	4	5
6. Even when I don't care about myself, other people do.	1	2	3	4	5
7. I understand how to control the symptoms of my mental illness.	1	2	3	4	5
8. I can handle it if I get sick again.	1	2	3	4	5
9. I can identify what triggers the symptoms of my mental illness.	1	2	3	4	5
10. I can help myself become better.	1	2	3	4	5
11. Fear doesn't stop me from living the way I want to.	1	2	3	4	5
12. I know that there are mental health services that do help me.	1	2	3	4	5
13. There are things that I can do that help me deal with unwanted symptoms.	1	2	3	4	5
14. I can handle what happens in my life.	1	2	3	4	5
15. I like myself.	1	2	3	4	5
16. If people really knew me, they would like me.	1	2	3	4	5
17. I am a better person than before my experience with mental illness.	1	2	3	4	5
18. Although my symptoms may get worse, I know I can handle it.	1	2	3	4	5
19. If I keep trying, I will continue to get better.	1	2	3	4	5

Recovery Assessment Scale (continued)	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
20. I have an idea of who I want to become	1	2	3	4	5
21. Things happen for a reason.	1	2	3	4	5
22. Something good will eventually happen.	1	2	3	4	5
23. I am the person most responsible for my own improvement.	1	2	3	4	5
24. I'm hopeful about my future.	1	2	3	4	5
25. I continue to have new interests.	1	2	3	4	5
26. It is important to have fun.	1	2	3	4	5
27. Coping with my mental illness is no longer the main focus of my life.	1	2	3	4	5
28. My symptoms interfere less and less with my life.	1	2	3	4	5
29. My symptoms seem to be a problem for shorter periods of time each time they occur.	1	2	3	4	5
30 . I know when to ask for help.	1	2	3	4	5
31. I am willing to ask for help.	1	2	3	4	5
32. I ask for help, when I need it.	1	2	3	4	5
33. Being able to work is important to me.	1	2	3	4	5
34. I know what helps me get better.	1	2	3	4	5
35. I can learn from my mistakes.	1	2	3	4	5
36. I can handle stress.	1	2	3	4	5
37. I have people I can count on.	1	2	3	4	5
38. I can identify the early warning signs of becoming sick.	1	2	3	4	5
39. Even when I don't believe in myself, other people do.	1	2	3	4	5
40. It is important to have a variety of friends.	1	2	3	4	5
41. It is important to have healthy habits.	1	2	3	4	5

Appendix C9: Recovery Assessment Scale – Domains and Stages

Name: .....

RAS-DS (Recovery Assessment Scale – Domains and Stages)

Instructions: Below is a list of statements that describe how people sometimes feel about themselves and their lives. Please read each one carefully and circle the number to the right that best describes you at the moment. Circle only one number for each statement and do not skip any items.

DOING THINGS I VALUE					
		UNTRUE	A bit TRUE	Mostly TRUE	Completely TRUE
1	It is important to have fun	1	2	3	4
2	It is important to have healthy habits	1	2	3	4
3	I do things that are meaningful to me	1	2	3	4
4	I continue to have new interests	1	2	3	4
5	I do things that are valuable and helpful to others	1	2	3	4
6	I do things that give me a feeling of great pleasure	1	2	3	4
LOOKING FORWARD					
		UNTRUE	A bit TRUE	Mostly TRUE	Completely TRUE
7	I can handle it if I get unwell again	1	2	3	4
8	I can help myself become better	1	2	3	4
9	I have the desire to succeed	1	2	3	4
10	I have goals in life that I want to reach	1	2	3	4
11	I believe that I can reach my current personal goals	1	2	3	4
12	I can handle what happens in my life	1	2	3	4
13	I like myself	1	2	3	4
14	I have a purpose in life	1	2	3	4
15	If people really knew me they would like me	1	2	3	4
16	If I keep trying, I will continue to get better	1	2	3	4
17	I have an idea of who I want to become	1	2	3	4
18	Something good will eventually happen	1	2	3	4
19	I am the person most responsible for my own improvement	1	2	3	4
20	I am hopeful about my own future	1	2	3	4
21	I know when to ask for help	1	2	3	4

LOOKING FORWARD (continued)					
		UNTRUE	A bit TRUE	Mostly TRUE	Completely TRUE
22	I ask for help, when I need it	1	2	3	4
23	I know what helps me get better	1	2	3	4
24	I can learn from my mistakes	1	2	3	4
MASTERING MY ILLNESS					
		UNTRUE	A bit TRUE	Mostly TRUE	Completely TRUE
25	I can identify the early warning signs of becoming unwell	1	2	3	4
26	I have my own plan for how to stay or become well	1	2	3	4
27	There are things that I can do that help me deal with unwanted symptoms	1	2	3	4
28	I know that there are mental health services that help me	1	2	3	4
29	Although my symptoms may get worse, I know I can handle it	1	2	3	4
30	My symptoms interfere less and less with my life	1	2	3	4
31	My symptoms seem to be a problem for shorter periods of time each time they occur	1	2	3	4
CONNECTING AND BELONGING					
		UNTRUE	A bit TRUE	Mostly TRUE	Completely TRUE
32	I have people that I can count on	1	2	3	4
33	Even when I don't believe in myself, other people do	1	2	3	4
34	It is important to have a variety of friends	1	2	3	4
35	I have friends who have also experienced mental illness	1	2	3	4
36	I have friends without mental illness	1	2	3	4
37	I have friends that can depend on me	1	2	3	4
38	I feel OK about my family situation	1	2	3	4

Recovery Assessment Scale – Domains and Stages (RAS-DS – Research Version 3).

Appendix C10: Review sheet for Delphi panel – round one

REVIEW SHEET DELPHI METHOD – ROUND 1			
ITEMS REPRESENTATIVE OF DEFINITION AND OPERATIONALISATION			
CATEGORIES AND ITEMS	**KEEP**	**DISCARD**	**COMMENTS**
CONNECTION AND SUPPORT FROM OR TO SERVICE USERS:			
I feel a (re-)connection with others			
I (can) communicate with others			
I (can) interact with others			
I (can) get along with others			
I feel a (re-)connection to my community			
I feel like a person who is part of my community			
I feel that I am supported			

I feel that I am supported by others			
I feel understood (by others)			
I provide support to others			
I feel that I inspire others			
I feel that I can be a role model to others			
ADAPT AND HOPE:			
I feel like I have adjusted to my mental illness			
I feel like I have adjusted to my situation			
I feel like I am making progress			
I feel like I am moving forward with my illness			
I am thinking in a positive way			
I feel like I can go on			
I can take small steps, into the future			

I can make plans (again) for the future			
IDENTITY, ROUTINE AND RENEWAL:			
I feel a (re-)connection with myself			
I feel like I am loved			
I have a role to play as a person			
I have a routine			
I feel like I have a new life (ahead of me)			
I am taking part in things that I did before			
I am even doing more things than I did before			
I feel again like the person I was before my mental illness			
MEANING, FAITH, CONTRIBUTION AND INSIGHT:			
I have meaning in my life			
I have purpose in my life			

My faith/belief/religion/prayer helps me			
My faith/belief/religion/prayer helps me to not feel alone			
I can live a normal life			
I can contribute to society			
I can acknowledge that I have a mental illness if I want to			
I accept my mental illness			
I know myself, who I am			
I know about my mental illness			
I am able to identify symptoms early, that can make me sick again			
INCOME, INDEPENDENCE, TRUST, AGENCY AND CAPACITY:			
Having a job is important to me			
Earning an income is important to me			

I have skills that can help me in my life			
I have skills that can help me with my illness			
I am responsible for myself			
I can make decisions for myself			
I feel that I am allowed to make decisions for myself			
I can take initiative to do things			
I feel like I am trusted by others			
I can do things that others can do			
I feel like I can cope with my mental illness			
CHALLENGES AND LIMITATIONS:			
I know how to deal with my stress			
Sometimes I feel like I am recovering and other times I don't feel like I am recovering			

I know my limitations			
I feel like recovery is difficult			
My environment makes my recovery difficult			
MEDICAL CONCEPTUALISATION:			
I feel better			
I feel healed			
I feel well			
I feel it is important for me to take my medication			
If I take my pills (medication), I will recover			
If I have no symptoms, I am recovering from my mental illness			
If I still take medication, I am not recovering from my mental illness			
When I get discharged, I don't have a mental illness anymore			

APPROPRIATE FORMAT AND STRUCTURE OF THE MEASURE	
ISSUE:	COMMENT:
HOW MEASURE IT SET OUT OVERALL	
EASE OF INSTRUCTIONS	
COMPLEXITY OF ITEMS	
SUITABILITY OF RESPONSE CHOICES	
ANY OTHER ISSUE REGARDING THE FORMAT OR STRUCTURE: (PLEASE FEEL FREE TO ADD EXTRA ROWS, IF NECESSARY)	COMMENT:

GENERAL COMMENTS	
ISSUE: (PLEASE FEEL FREE TO ADD EXTRA ROWS, IF NECESSARY)	COMMENT:

Appendix C11: Matching randomly ordered items with dimensions: Part 1

	Dimension 1	Dimension 2	Dimension 3	Dimension 4	Dimension 5	Dimension 6	Dimension 7
Dimension of recovery ➜	Collaborate, Connection and Support from or to service users	Adapt and Hope	Identity, Routine and Renewal	Meaning, Faith, Contribution and Insight	Income, Independence, Trust, Agency and Capacity	Medical conceptualisation	Challenges and limitations
Explanation of dimension➜	The importance of relationships with others for service users in their recovery process.	The wish of service users to move positively forward with their lives and to see a future for themselves with their mental illness.	The service users' relationships with themselves and (re-)building those relationships.	The need in service users' recovery process to also relate to, or make sense of their experiences in, the world around them.	Service users (re-)gaining strength to function in the world, despite their mental illness.	The understanding of recovery by service users in a medical/clinical way.	Acknowledgement of difficulties, even impossibilities, faced by participants, in the recovery process.
Items ⬇							
I (can) communicate with others							
When I get discharged, I don't have a mental illness anymore							
I feel again like the person I was before my mental illness							
I feel that I am supported by others							
If I still take medication, I am not recovering from my mental illness							
I feel like I am moving forward with my illness							
My faith/belief/religion/prayer helps me to not feel alone							
I am thinking in a positive way							
I have a role to play as a person							
I am taking part in things that I did before							
I am able to identify symptoms early, that can make me sick again							
I (can) get along with others							
Earning an income is important to me							
I feel like I am making progress							
I feel like I have adjusted to my situation							
I feel healed							
If I have no symptoms, I am recovering from my mental illness							
My environment makes my recovery difficult							
I feel a (re-)connection to my community							
I feel that I can be a role model to others							
I feel like I have adjusted to my mental illness							
Having a job is important to me							
I have skills that can help me with my illness							
I can do things that others can do							
I can make decisions for myself							
I have a routine							

I am responsible for myself							
I feel like I am trusted by others							
I feel better							
I am even doing more things than I did before							
I (can) interact with others							
I feel like I can go on							
I can make plans (again) for the future							
I feel like I am loved							
I know about my mental illness							
I feel that I am allowed to make decisions for myself							
I know my limitations							
I feel like I can cope with my mental illness							
I can take small steps, into the future							
I can contribute to society							
I can take initiative to do things							
I can acknowledge that I have a mental illness if I want to							
I feel a (re-)connection with others							
I can live a normal life							
I have purpose in my life							
I provide support to others							
If I take my pills (medication), I will recover							
My faith/belief/religion/prayer helps me							
I know how to deal with my stress							
I have meaning in my life							
I feel like a person who is part of my community							
I feel that I am supported							
I have skills that can help me in my life							
I feel like recovery is difficult							
Sometimes I feel like I am recovering and other times I don't feel like I am recovering							
I know myself, who I am							
I accept my mental illness							
I feel it is important for me to take my medication							
I feel like I have a new life (ahead of me)							
I feel that I inspire others							
I feel a (re-)connection with myself							
I feel well							
I feel understood (by others)							

Appendix C12: Examples of changes made to measure after Delphi panel and matching of items: Part 1

Some examples of the changes, that I made to the wording of the measure, in line with the results from the matching-of-items-with-dimensions exercise and the Delphi panel and the comments from the Delphi panellists, as well as revisiting some of the earlier problems identified by the psychometry academic during item development and drafting of the measure, were:

1. Changing wording of items that reflect an ability, to wording that reflects an action, for example, from *I can communicate with others,* to *I communicate with others.*
2. Changing metaphorical language to more direct statements, for example, from *I can take small steps, into the future,* to *I set goals for my future.*
3. Making the wording of an item more concrete, for example, from *I have a role to play as a person*, to *I feel I have a place in my community.*
4. Clarifying the wording of the item, for example, from *I know myself, who I am* to *Through my mental health recovery, I have learnt about myself.*

I moved some items from one dimension to another, on advice of the Delphi panel and the psychometry academic, who advised me during item development and the drafting of the measure, combined with the results from the matching-of-items-with-dimensions exercise. For example, I moved *I am able to identify triggers early, that can make me sick again* from the dimension, *Relating to the world*, to the dimension, *Clinical understanding to support personal recovery*.

Furthermore, based on comments by the Delphi panellists together with the advice from the psychometry academic, who advised me during item development and the drafting of the measure, I changed the fifth response option in the measure from *Very much* to *Completely* to better clarify the distinction between the response categories and to minimise

possible overlap between the response options. I also added descriptions of the response options and an example statement at the start of the measure, which could be used to explain the answering of statements to participants during future administration. The purpose of the example statement is to familiarise participants with the format of and the items in the measure before they started to complete it.

I also addressed two dilemmas that presented themselves during the analysis of the results from the Delphi panel. The first dilemma was that one item that was to be included, according to the results, was identified by one of the panellists as potentially negative and tapping into suicidal tendencies. This item was formulated as; *I feel like I can go on.* The dilemma with this item was, if a respondent were to answer no, it might bring up negative thought patterns, even suicidal thoughts, and could break down possible gains that the respondent had made in their recovery journey. Taking into account the vulnerability and my ethical duty as researcher to minimise potential harm to my participants, who form part of a highly stigmatised population and are therefore particularly vulnerable, I decided to exclude this item from the measure. The other dilemma was that I remembered that another item, which was to be excluded according to the results of the Delphi panel, was emphasised by many interview and focus group participants as an important part of their recovery process. This item was formulated as, *Earning an income is important to me.* I considered my own bias in identifying this item as needing to be included despite the Delphi panel results and consulted the qualitative data again in making a final decision on whether to include this item. Based on the aforegoing, I decided to include this item in the measure presented to the cognitive interview participants and thereafter make a final decision on the item, based on their feedback.

Appendix C13: Spreadsheet for analysis of results of cognitive interviews

	CONSTRUCT: MENTAL HEALTH RECOVERY				
No	**Item**	**Dimension**	**Intent**	**Anticipated relevant cognitive operation**	**Probes**
				1) Understanding (Is the statement clear and easy to understand?) / **2) Retrieval** (Does the P have the knowledge or formed an attitude to reply? Is the statement too difficult for memory process of P?) / **3) Judgement** (Is the item asking about too sensitive info? Is the item relevant?) / **4) Response** (Do the response options suit the reply P wants to give? Are the response options clear?)	
1	I feel a connection with others that support me.	Connection & Support from and to service users	To assess SU's perception of their own connection with supportive others.	Understanding; Retrieval	What were you thinking of when I asked about *connection*? What does *others that support me* mean to you? Before I asked this question about *connection* and *support,* how much had you thought about it?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
2	I communicate with others.	Connection & Support from and to service users	To assess SU's perception of their own communicative connections with others.	Understanding	What does the word *communicate* mean to you? Who were you thinking of when I asked about *others*? How comfortable did you feel answering this question?
3	I interact with others.	Connection & Support from and to service users	To assess SU's perception of their own connections through interaction.	Understanding; Retrieval	What does the word *interact* mean to you? Before I asked this question about *interacting with others*, how much had you thought about it?
4	I get along with others.	Connection & Support from and to service users	To assess SU's perception of their own connections by getting along with others.	Understanding; Retrieval	What do the words *get along* mean to you? Who were you thinking of when I asked about *others*? Before I asked this question about *getting along with others*, how much had you thought about it?
5	I feel a positive connection to my community.	Connection & Support from and to service users	To assess SU's perception of their own positive connection to community.	Understanding; Retrieval	What do the words *positive connection* mean to you? What does *my community* mean to you? Before I asked this question about *positive connection* and *your community*, how much had you thought about it?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
6	I feel like I am part of my community.	Connection & Support from and to service users	To assess SU's perception of themselves supported by being part of community.	Retrieval (Judgement)	Before I asked this question about *being part of your community*, how much had you thought about it?
7	I feel that I am supported, emotionally, financially or otherwise, by others.	Connection & Support from and to service users	To assess SU's perception of themselves supported, in different ways, by others.	Understanding; Retrieval (Judgement)	What does the word *supported* mean to you? Are the examples of support applicable to you? Are there other examples of support applicable to you? What are those examples for you? Before I asked this question about *support to you by others*, how much had you thought about it?
8	I support others, either emotionally, financially or otherwise.	Connection & Support from and to service users	To assess SU's perception of themselves supporting others, in different ways.	Understanding; Retrieval (Judgement)	What do the words *I support others* mean to you? Are the examples of support applicable for you? Are there other examples of support applicable for you? What are those other examples for you? Before I asked this question about *you supporting others*, how much had you thought about it?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
9	I feel that I am a role model to others because of my mental health recovery.	Connection & Support from and to service users	To assess SU's perception of themselves supporting others by being a role model to them.	Understanding; Retrieval (Judgement)	What do the words *role model* mean to you? What do the words *mental health recovery* mean to you? Before I asked this question about *you being a role model*, how much had you thought about it?
10	I feel like I have adjusted to my mental health situation.	Adapt & Hope	To assess SU's perception of their own adjustment to their MH situation.	Understanding; Retrieval	What does the word *adjusted* mean to you? What do the words *mental health situation* mean to you? Before I asked this question about *your adjustment to your MH situation*, how much had you thought about it?
11	I feel like I am making progress with my mental health recovery.	Adapt & Hope	To assess SU's perception of their own progress with their MH recovery.	Understanding; Retrieval	What do the words *making progress* mean to you? Before I asked this question about *you making progress*, how much had you thought about it?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
12	I feel like I am moving forward with how I live with my mental health recovery.	Adapt & Hope	To assess SU's perception of whether they move forward with how they live with their own MH recovery.	Understanding; Retrieval	What do the words *moving forward* mean to you? What do the words mental health recovery mean to you? Before I asked this question about *you moving forward*, how much had you thought about it?
13	I am thinking in a positive way about my mental health.	Adapt & Hope	To assess SU's perception of themselves thinking positively about their own MH.	Retrieval	Before I asked this question about *you thinking in a positive way about your MH,* how much had you thought about it?
14	I set goals for my future.	Adapt & Hope	To assess SU's perception of whether they set goals for their own future.	Understanding; Retrieval (Judgement)	What does the word *goals* mean to you? Before I asked this question about *setting goals for your future*, how much had you thought about it?
15	I make plans for my future.	Adapt & Hope	To assess SU's perception of whether they make plans for their own future.	Understanding; Retrieval (Judgement)	What does the word *plans* mean to you? Before I asked this question about *making plans for your future*, how much had you thought about it?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
16	I feel like I have a new life ahead of me.	Adapt & Hope	To assess SU's perception of whether they feel they have a new lease on their own life.	Retrieval	Before I asked this question about *your new life*, how much had you thought about it?
17	Even though recovery has ups and downs, overall I feel like I am moving in a positive direction.	Adapt & Hope	To assess SU's perception of whether they feel are positively moving forward despite recovery's ups & downs.	Understanding; Retrieval	What do the words *ups and downs* mean to you? What do the words *moving in a positive direction* mean to you? Before I asked this question about *moving in a positive direction despite ups and downs*, how much had you thought about it?
18	I understand myself better through my mental health recovery.	Identity, Routine & Renewal	To assess SU's perception of their own understanding of themselves because of their MH recovery.	Understanding; Retrieval	What do the words *understand myself better* mean to you? Before I asked this question about *you understanding yourself better through your recovery* how much had you thought about it?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
19	I feel I have a place in my community.	Identity, Routine & Renewal	To assess SU's perception of whether they have a place in their own community.	Retrieval (Judgement)	Before I asked this question about *your place in your community*, how much had you thought about it?
20	I have a routine for my daily tasks.	Identity, Routine & Renewal	To assess SU's perception of whether they are using a routine to get through their daily tasks.	Understanding; Retrieval (Judgement)	What does the word *routine* mean to you? What do the words *daily tasks* mean to you? Before I asked this question about *your routine*, how much had you thought about it?
21	I am doing things (like hobbies, interests, or social activities) that I did before.	Identity, Routine & Renewal	To assess SU's perception of them doing various positive activities that they did before their MI.	Understanding; Retrieval (Judgement)	What do the words *did before* mean to you? Are the examples of *things you do* applicable to you? Are there other examples of *things you do* applicable to you? What are those examples? Before I asked this question about *your doing things*, how much had you thought about it?
22	I am doing new things.	Identity, Routine & Renewal	To assess SU's perception of them doing new things.	Retrieval (Judgement)	Before I asked this question about *your doing new things*, how much had you thought about it?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
23	I have meaning in my life.	Meaning, Faith, Contribution & Insight	To assess SU's perception of whether they have meaning (linked more to spiritual aspects) in their life.	Retrieval (Judgement)	Before I asked this question about *meaning in your life* how much had you thought about it?
24	I have purpose in my life.	Meaning, Faith, Contribution & Insight	To assess SU's perception of whether they have purpose (linked more to functional aspects) in their life.	Retrieval (Judgement)	Before I asked this question about *purpose in your life*, how much had you thought about it?
25	Faith/belief/ religion/pra yer/spiritual ity helps me.	Meaning, Faith, Contribution & Insight	To assess SU's perception of whether spiritual experiences/activities help them.	Understanding (Judgement)	Are the examples of religion or faith applicable to you? (If yes:) Which ones? Are there other examples of religion or faith applicable to you? What are those examples?
26	I feel that I contribute to society in positive ways.	Meaning, Faith, Contribution & Insight	To assess SU's perception of whether they make a positive contribution to society.	Understanding; Retrieval	What does the word *contribute* mean to you? What do the words *positive ways* mean to you? Before I asked this question about *you contributing in positive ways to society*, how much had you thought about it?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
27	Through my mental health recovery, I have learnt about myself.	Meaning, Faith, Contribution & Insight	To assess SU's perception of whether their MH recovery has taught them about themselves.	Understanding; Retrieval	What do the words *learnt about myself* mean to you? Before I asked this question about *you learning about yourself*, how much had you thought about it?
28	Earning an income is important to me.	Income, Independence, Trust, Agency & Capacity	To assess SU's perception of whether earning an income is important to them in their MH recovery.	Understanding	What do the words *earning an income* mean to you?
29	I have skills that can help me live my life positively.	Income, Independence, Trust, Agency & Capacity	To assess SU's perception of whether they have skills that contribute to them living a positive life, so they have capacity.	Understanding; Retrieval (Judgement)	What does the word *skills* mean to you? What do the words *live my life positively* mean to you? Before I asked this question about *you having skills to life your life positively*, how much had you thought about it?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
30	I have skills that can help me live positively with my mental health recovery.	Income, Independence, Trust, Agency & Capacity	To assess SU's perception of whether they have skills that contribute to them living a positive life, with their MH recovery, so they have capacity.	Understanding; Retrieval (Judgement)	Does this question differ for you from the previous question? Which is the better question for you? Before I asked this question about *you having skills to life your life positively with your MH recovery*, how much had you thought about it?
31	I take responsibility for myself.	Income, Independence, Trust, Agency & Capacity	To assess SU's perception of their own responsibility-taking for themselves, to be independent.	(Judgement)	
32	I make decisions for myself.	Income, Independence, Trust, Agency & Capacity	To assess SU's perception of their own ability to make decisions for themselves to have agency/independence.	Retrieval	Before I asked this question about *making decision for yourself* how much had you thought about it?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
33	I have good judgement to decide what's good or bad for me.	Income, Independence, Trust, Agency & Capacity	To assess SU's perception of whether they judge what is good/bad for them, to be independent and trusted.	Understanding; Retrieval (Judgement)	What do the words *good judgement* mean to you? Before I asked this question about *your judgement about things that are good of bad for you*, how much had you thought about it?
34	I decide for myself to do things.	Income, Independence, Trust, Agency & Capacity	To assess SU's perception of whether they decide themselves to do things, to have agency.	Retrieval (Judgement)	Before I asked this question about *deciding for yourself to do things*, how much had you thought about it?
35	I feel like other people trust me.	Income, Independence, Trust, Agency & Capacity	To assess SU's perception of whether they feel others trust them, so they have trust/agency.	(Judgement)	
36	I feel like I am just as able as other people to do things.	Income, Independence, Trust, Agency & Capacity	To assess SU's perception of whether they feel they can do things just as others can, so they have capacity.	Understanding (Judgement)	What do the words *just as able as other people* mean to you?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
37	I feel like I can manage with my mental health recovery.	Income, Independence, Trust, Agency & Capacity	To assess SU's perception of whether they feel they can cope with their MH recovery, so they have capacity.	Understanding; Retrieval	What does the word *manage* mean to you? Before I asked this question about *your managing with your MH recovery,* how much had you thought about it?
38	I feel that I am able to deal with my stress.	Challenges & Limitations	To assess SU's perception of whether they can deal with stress in their life (and MH recovery), as a challenge.	Understanding; Retrieval	What do the words *able to deal with my stress* mean to you? Before I asked this question about *your ability to deal with your stress,* how much had you thought about it?
39	I know the challenges of my mental health recovery.	Challenges & Limitations	To assess SU's awareness of the challenges they face with their MH recovery.	Understanding; Retrieval	What do the words *challenges of my MH recovery* mean to you? Before I asked this question about *your knowledge about your MH recovery challenges*, how much had you thought about it?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
40	Sometimes I feel like mental health recovery is difficult.	Challenges & Limitations	To assess SU's perception of whether they feel MH recovery is difficult, as an awareness of challenges/limitations to MH recovery.	(Judgement)	
41	Sometimes my environment (like family/friends/work/where I live) makes my recovery difficult.	Challenges & Limitations	To assess whether SUs perceive various aspects of their environment to place additional challenges/limitations on their MH recovery.	Understanding; Retrieval	What does the word *environment* mean to you? Are the examples of *your environment* in the question applicable to you? Are there other examples of *your environment* applicable to you? What are those examples? Before I asked this question about *your environment that might make your MH recovery difficult*, how much had you thought about it?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
42	I feel better than I did before.	Medical conceptualisation	To assess SU's perception of whether they are making progress in their MH recovery in feeling better.	Understanding; Retrieval	What does the word *better* mean to you? Before I asked this question about *you feeling better than before*, how much had you thought about it?
43	If I have to take medicine, I feel it is important that I take it.	Medical conceptualisation	To assess SU's perception of whether they regard the taking of meds as important for them.	Retrieval (Judgement)	Before I asked this question about *whether it is important to take medicine,* how much had you thought about it?
44	I feel that it will help me to recover if I take my medicine.	Medical conceptualisation	To assess SU's perception of whether they feel that taking meds will help along their MH recovery.	Understanding; Retrieval	Is this sentence easily understandable to you? Before I asked this question about *whether you feel it will help you recover if you take your medicine*, how much had you thought about it?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
45	I can still be recovering if I have symptoms.	Medical conceptualisation	To assess SU's perception of whether MH recovery is possible for them despite symptoms.	Understanding; Retrieval	Is this sentence easily understandable to you? What does *recovering* mean to you? Before I asked this question about *recovering with symptoms* how much had you thought about it?
46	Being discharged means I am mentally healthy.	Medical conceptualisation	To assess SU's perception of whether they must be completely recovered (mentally healthy) when discharged.	Understanding; (Judgement)	What does *mentally healthy mean to you?*
47	I have information about my mental illness.	Medical conceptualisation	To assess SU's perception of whether they are informed about their MI.	Understanding	What does the word *information* mean to you?

No	Item	Dimension	Intent	Anticipated relevant cognitive operation	Probes
48	I am able to identify triggers early, that can make me sick again.	Medical conceptualisation	To assess SU's perception of whether they will be able to notice triggers that could signify becoming ill again.	Understanding; Retrieval (Judgement)	Is this sentence easily understandable to you? What does the word *triggers* mean to you? Before I asked this question about *identifying triggers early to not get sick again*, how much had you thought about it?
Judgement					Were there questions of which you thought that one of the response options has to be the right answer? How comfortable did you feel answering these questions? Were there questions that made you feel awkward or uncomfortable? (If yes:) Can you point out those questions to me?

Response options	Were you able to find your answer from the response options shown?
	Was there an answer that you wanted to give that was not available in the response options?
	Were there response options that did not make sense to you?
Construct - adequacy of content	What do you think about this questionnaire?
	This questionnaire was about Mental Health Recovery. Was there anything not included in these questions that is important to you regarding Mental Health Recovery?

Appendix C14: Spreadsheet for use during cognitive interviews

CONSTRUCT: MENTAL HEALTH RECOVERY				
No	**Item**	**Thinking-aloud (TA)**	**Verbal Probes (VP)**	**Participant answers**
1	I feel a connection with others that support me.	Prompt participant to think aloud.	What were you thinking of when I asked about *connection*? What does *others that support me* mean to you? Before I asked this question about *connection* and *support,* how much had you thought about it?	
2	I communicate with others.	Prompt participant to think aloud.	What does the word *communicate* mean to you? Who were you thinking of when I asked about *others*? How comfortable did you feel answering this question?	
3	I interact with others.	Prompt participant to think aloud.	What does the word *interact* mean to you? Before I asked this question about *interacting with others*, how much had you thought about it?	
4	I get along with others.	Prompt participant to think aloud.	What do the words *get along* mean to you? Who were you thinking of when I asked about *others*? Before I asked this question about *getting along with others*, how much had you thought about it?	

No	Item	Thinking-aloud (TA)	Verbal Probes (VP)	Participant answers
5	I feel a positive connection to my community.	Prompt participant to think aloud.	What do the words *positive connection* mean to you? What does *my community* mean to you? Before I asked this question about *positive connection* and *your community*, how much had you thought about it?	
6	I feel like I am part of my community.	Prompt participant to think aloud.	Before I asked this question about *being part of your community*, how much had you thought about it?	
7	I feel that I am supported, emotionally, financially or otherwise, by others.	Prompt participant to think aloud.	What does the word *supported* mean to you? Are the examples of support applicable to you? Are there other examples of support applicable to you? What are those examples for you? Before I asked this question about *support to you by others*, how much had you thought about it?	
8	I support others, either emotionally, financially or otherwise.	Prompt participant to think aloud.	What do the words *I support others* mean to you? Are the examples of support applicable for you? Are there other examples of support applicable for you? What are those other examples for you? Before I asked this question about *you supporting others*, how much had you thought about it?	

No	Item	Thinking-aloud (TA)	Verbal Probes (VP)	Participant answers
9	I feel that I am a role model to others because of my mental health recovery.	Prompt participant to think aloud.	What do the words *role model* mean to you? What do the words *mental health recovery* mean to you? Before I asked this question about *you being a role model*, how much had you thought about it?	
10	I feel like I have adjusted to my mental health situation.	Prompt participant to think aloud.	What does the word *adjusted* mean to you? What do the words *mental health situation* mean to you? Before I asked this question about *your adjustment to your MH situation*, how much had you thought about it?	
11	I feel like I am making progress with my mental health recovery.	Prompt participant to think aloud.	What do the words *making progress* mean to you? Before I asked this question about *you making progress*, how much had you thought about it?	

No	Item	Thinking-aloud (TA)	Verbal Probes (VP)	Participant answers
12	I feel like I am moving forward with how I live with my mental health recovery.	Prompt participant to think aloud.	What do the words *moving forward* mean to you? What do the words mental health recovery mean to you? Before I asked this question about *you moving forward*, how much had you thought about it?	
13	I am thinking in a positive way about my mental health.	Prompt participant to think aloud.	Before I asked this question about *you thinking in a positive way about your MH,* how much had you thought about it?	
14	I set goals for my future.	Prompt participant to think aloud.	What does the word *goals* mean to you? Before I asked this question about *setting goals for your future*, how much had you thought about it?	
15	I make plans for my future.	Prompt participant to think aloud.	What does the word *plans* mean to you? Before I asked this question about *making plans for your future*, how much had you thought about it?	

No	Item	Thinking-aloud (TA)	Verbal Probes (VP)	Participant answers
16	I feel like I have a new life ahead of me.	Prompt participant to think aloud.	Before I asked this question about *your new life*, how much had you thought about it?	
17	Even though recovery has ups and downs, overall I feel like I am moving in a positive direction.	Prompt participant to think aloud.	What do the words *ups and downs* mean to you? What do the words *moving in a positive direction* mean to you? Before I asked this question about *moving in a positive direction despite ups and downs*, how much had you thought about it?	
18	I understand myself better through my mental health recovery.	Prompt participant to think aloud.	What do the words *understand myself better* mean to you? Before I asked this question about *you understanding yourself better through your recovery* how much had you thought about it?	
19	I feel I have a place in my community.	Prompt participant to think aloud.	Before I asked this question about *your place in your community*, how much had you thought about it?	

No	Item	Thinking-aloud (TA)	Verbal Probes (VP)	Participant answers
20	I have a routine for my daily tasks.	Prompt participant to think aloud.	What does the word *routine* mean to you? What do the words *daily tasks* mean to you? Before I asked this question about *your routine*, how much had you thought about it?	
21	I am doing things (like hobbies, interests, or social activities) that I did before.	Prompt participant to think aloud.	What do the words *did before* mean to you? Are the examples of *things you do* applicable to you? Are there other examples of *things you do* applicable to you? What are those examples? Before I asked this question about *your doing things*, how much had you thought about it?	
22	I am doing new things.	Prompt participant to think aloud.	Before I asked this question about *your doing new things*, how much had you thought about it?	
23	I have meaning in my life.	Prompt participant to think aloud.	Before I asked this question about *meaning in your life* how much had you thought about it?	
24	I have purpose in my life.	Prompt participant to think aloud.	Before I asked this question about *purpose in your life*, how much had you thought about it?	

No	Item	Thinking-aloud (TA)	Verbal Probes (VP)	Participant answers
25	Faith/belief/ religion/prayer /spirituality helps me.	Prompt participant to think aloud.	Are the examples of religion or faith applicable to you? (If yes:) Which ones? Are there other examples of religion or faith applicable to you? What are those examples?	
26	I feel that I contribute to society in positive ways.	Prompt participant to think aloud.	What does the word *contribute* mean to you? What do the words *positive ways* mean to you? Before I asked this question about *you contributing in positive ways to society*, how much had you thought about it?	
27	Through my mental health recovery, I have learnt about myself.	Prompt participant to think aloud.	What do the words *learnt about myself* mean to you? Before I asked this question about *you learning about yourself*, how much had you thought about it?	
28	Earning an income is important to me.	Prompt participant to think aloud.	What do the words *earning an income* mean to you?	
29	I have skills that can help me live my life positively.	Prompt participant to think aloud.	What does the word *skills* mean to you? What do the words *live my life positively* mean to you? Before I asked this question about *you having skills to life your life positively*, how much had you thought about it?	

No	Item	Thinking-aloud (TA)	Verbal Probes (VP)	Participant answers
30	I have skills that can help me live positively with my mental health recovery.	Prompt participant to think aloud.	Does this question differ for you from the previous question? Which is the better question for you? Before I asked this question about *you having skills to life your life positively with your MH recovery*, how much had you thought about it?	
31	I take responsibility for myself.	Prompt participant to think aloud.		
32	I make decisions for myself.	Prompt participant to think aloud.	Before I asked this question about *making decision for yourself* how much had you thought about it?	
33	I have good judgement to decide what's good or bad for me.	Prompt participant to think aloud.	What do the words *good judgement* mean to you? Before I asked this question about *your judgement about things that are good of bad for you*, how much had you thought about it?	

No	Item	Thinking-aloud (TA)	Verbal Probes (VP)	Participant answers
34	I decide for myself to do things.	Prompt participant to think aloud.	Before I asked this question about *deciding for yourself to do things*, how much had you thought about it?	
35	I feel like other people trust me.	Prompt participant to think aloud.		
36	I feel like I am just as able as other people to do things.	Prompt participant to think aloud.	What do the words *just as able as other people* mean to you?	
37	I feel like I can manage with my mental health recovery.	Prompt participant to think aloud.	What does the word *manage* mean to you? Before I asked this question about *your managing with your MH recovery,* how much had you thought about it?	
38	I feel that I am able to deal with my stress.	Prompt participant to think aloud.	What do the words *able to deal with my stress* mean to you? Before I asked this question about *your ability to deal with your stress,* how much had you thought about it?	

No	Item	Thinking-aloud (TA)	Verbal Probes (VP)	Participant answers
39	I know the challenges of my mental health recovery.	Prompt participant to think aloud.	What do the words *challenges of my MH recovery* mean to you? Before I asked this question about *your knowledge about your MH recovery challenges*, how much had you thought about it?	
40	Sometimes I feel like mental health recovery is difficult.	Prompt participant to think aloud.		
41	Sometimes my environment (like family/friends/ work/where I live) makes my recovery difficult.	Prompt participant to think aloud.	What does the word *environment* mean to you? Are the examples of *your environment* in the question applicable to you? Are there other examples of *your environment* applicable to you? What are those examples? Before I asked this question about *your environment that might make your MH recovery difficult*, how much had you thought about it?	

No	Item	Thinking-aloud (TA)	Verbal Probes (VP)	Participant answers
42	I feel better than I did before.	Prompt participant to think aloud.	What does the word *better* mean to you? Before I asked this question about *you feeling better than before*, how much had you thought about it?	
43	If I have to take medicine, I feel it is important that I take it.		Before I asked this question about *whether it is important to take medicine,* how much had you thought about it?	
44	I feel that it will help me to recover if I take my medicine.		Is this sentence easily understandable to you? Before I asked this question about *whether you feel it will help you recover if you take your medicine*, how much had you thought about it?	
45	I can still be recovering if I have symptoms.		Is this sentence easily understandable to you? What does *recovering* mean to you? Before I asked this question about *recovering with symptoms* how much had you thought about it?	
46	Being discharged means I am mentally healthy.		What does *mentally healthy mean to you?*	

No	Item	Thinking-aloud (TA)	Verbal Probes (VP)	Participant answers
47	I have information about my mental illness.		What does the word *information* mean to you?	
48	I am able to identify triggers early, that can make me sick again.		Is this sentence easily understandable to you? What does the word *triggers* mean to you? Before I asked this question about *identifying triggers early to not get sick again*, how much had you thought about it?	
Judgement			Were there questions of which you thought that one of the response options has to be the right answer? Were all the questions relevant to you? Which ones where not relevant to you - can you point out those questions to me? How comfortable did you feel answering these questions? Were there questions that made you feel awkward or uncomfortable? (If yes:) Can you point out those questions to me?	

Response options	Were you able to find your answer from the response options shown?	
	Was there an answer that you wanted to give that was not available in the response options?	
	Were there response options that did not make sense to you?	
Construct - adequacy of content	What do you think about this questionnaire?	
	This questionnaire was about Mental Health Recovery. Was there anything not included in these questions that is important to you regarding Mental Health Recovery?	

Appendix C15: Version of measure for cognitive interviews

PRELIMINARY VERSION II – SUBJECT TO CHANGE

MEASURE OF INDIVIDUAL MENTAL HEALTH RECOVERY FOR THE SOUTH AFRICAN CONTEXT (MIMHR-SA)

This is a list of statements about how you might think and feel about yourself, your health, your life and your environment. By completing it you will help us to understand more about the process of your mental health recovery. The process of recovery is different for each person, so there are no right or wrong answers. By completing this, we hope that the results will also help you to understand more about your own recovery process. Please use the results from this to discuss and/or plan your mental health recovery with your service provider or people close to you that you trust.

Name: ……..

Date: ……..

How much do you agree with each statement below?
(Read and think about each statement carefully. Use the boxes on the right to mark the answer that best fits each statement for you. Only mark one box per statement. Please do not skip any statements.)

Example statement:

		"I don't agree with the statement in any way."	"I agree with the statement to a small degree."	"I agree with the statement more than a little bit, but not yet a lot."	"I agree with the statement a lot, but not completely."	"I agree with the statement in every way."
		Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Completely**
	Through my mental health recovery, I have learnt about my strengths and weaknesses.	1	2	3	4	5

PRELIMINARY VERSION II – SUBJECT TO CHANGE

		Not at all	A little bit	Somewhat	Quite a bit	Completely
1	I feel a connection with others that support me.	1	2	3	4	5
2	I communicate with others.	1	2	3	4	5
3	I interact with others.	1	2	3	4	5
4	I get along with others.	1	2	3	4	5
5	I feel a positive connection to my community.	1	2	3	4	5
6	I feel like I am part of my community.	1	2	3	4	5
7	I feel that I am supported, emotionally, financially or otherwise, by others.	1	2	3	4	5
8	I support others, either emotionally, financially or otherwise.	1	2	3	4	5
9	I feel that I am a role model to others because of my mental health recovery.	1	2	3	4	5
10	I feel like I have adjusted to my mental health situation.	1	2	3	4	5
11	I feel like I am making progress with my mental health recovery.	1	2	3	4	5
12	I feel like I am moving forward with how I live with my mental health recovery.	1	2	3	4	5
13	I am thinking in a positive way about my mental health.	1	2	3	4	5
14	I set goals for my future.	1	2	3	4	5
15	I make plans for my future.	1	2	3	4	5
16	I feel like I have a new life ahead of me.	1	2	3	4	5
17	Even though recovery has ups and downs, overall I feel like I am moving in a positive direction.	1	2	3	4	5
18	I understand myself better through my mental health recovery.	1	2	3	4	5
19	I feel I have a place in my community.	1	2	3	4	5

PRELIMINARY VERSION II – SUBJECT TO CHANGE

		Not at all	A little bit	Somewhat	Quite a bit	Completely
20	I have a routine for my daily tasks.	1	2	3	4	5
21	I am doing things (like hobbies, interests, or social activities) that I did before.	1	2	3	4	5
22	I am doing new things.	1	2	3	4	5
23	I have meaning in my life.	1	2	3	4	5
24	I have purpose in my life.	1	2	3	4	5
25	Faith/belief/religion/prayer/spirituality helps me.	1	2	3	4	5
26	I feel that I contribute to society in positive ways.	1	2	3	4	5
27	Through my mental health recovery, I have learnt about myself.	1	2	3	4	5
28	Earning an income is important to me.	1	2	3	4	5
29	I have skills that can help me live my life positively.	1	2	3	4	5
30	I have skills that can help me live positively with my mental health recovery.	1	2	3	4	5
31	I take responsibility for myself.	1	2	3	4	5
32	I make decisions for myself.	1	2	3	4	5
33	I have good judgement to decide what's good or bad for me.	1	2	3	4	5
34	I decide for myself to do things.	1	2	3	4	5
35	I feel like other people trust me.	1	2	3	4	5
36	I feel like I am just as able as other people to do things.	1	2	3	4	5
37	I feel like I can manage with my mental health recovery.	1	2	3	4	5
38	I feel that I am able to deal with my stress.	1	2	3	4	5
39	I know the challenges of my mental health recovery.	1	2	3	4	5

PRELIMINARY VERSION II – SUBJECT TO CHANGE

		Not at all	A little bit	Somewhat	Quite a bit	Completely
40	Sometimes I feel like mental health recovery is difficult.	1	2	3	4	5
41	Sometimes my environment (like family/friends/work/where I live) makes my recovery difficult.	1	2	3	4	5
42	I feel better than I did before.	1	2	3	4	5
43	If I have to take medicine, I feel it is important that I take it.	1	2	3	4	5
44	I feel that it will help me to recover if I take my medicine.	1	2	3	4	5
45	I can still be recovering if I have symptoms.	1	2	3	4	5
46	Being discharged means I am mentally healthy.	1	2	3	4	5
47	I have information about my mental illness.	1	2	3	4	5
48	I am able to identify triggers early, that can make me sick again.	1	2	3	4	5

Thank you very much for your answers and contribution! ☺

Appendix C16: Interview protocol for cognitive interviews

Interview schedule – cognitive interviews with service users

Introduction

Good day, you might remember me from the interview I did with you in 2018. Thank you for being willing to participate again in this part of my study. I will need your consent again to do this. I will explain this to you in more detail.

If you remember from before, my study is about mental health recovery. I used the previous information that you and others gave me about your thoughts and experiences of mental health recovery to come up with a list of questions that people can answer if they want to know about their mental health recovery.

I plan to ask you and a selected few other people whether these questions are correct and whether the questionnaire works for you.

After I have received the feedback from you and the others, in these interviews, I will look at it and work to adapt the questionnaire for others here at the hospital and other hospitals to test out.

I would like to make notes during this interview please. This is to make sure I remember what you and the other participants have said.

Is that OK?

I will then write about it in my thesis and in articles.

Do you understand what I have said so far?

Remember, it is important that you know that you are completely free to choose to take part in this part of my study or not. If you choose not to take part, it will not affect your participation in other activities or services at the hospital. Also, once you have chosen to take part, you are also free to choose to not take part anymore at any time before, during or after this interview. Any information that I would have already received from you then will not be used in the study.

Also, I will not reveal your name to anyone except my lecturer. So, no-one except me and my lecturer will know that it was you who said the things you did. I will also not share any part of what you have told me with anyone else, except my lecturer, before giving you another name and take out other details that might identify you so people who read or hear about it cannot easily identify you. Once I have done that, I will be able to share what you have told me with those persons who will evaluate my thesis, professional persons at the hospitals and through publication in professional journals.

If you feel uncomfortable at any stage during or directly after the interviews, you are welcome to tell me and I will stop the interview, as the case may be, and ensure that a professional person

is available to talk to you about what is bothering you. I also need to inform you that you will not receive any money or anything else for participating in this research project except a contribution toward your travelling costs, if applicable.

Do you consent to all these things that I have explained to you?

Could you please sign this consent form?

It is very similar to the one that you signed before.

The interview should take about 60-120 minutes.

Of course, once again, you are free to end the interview at any time, should you not wish to continue with it.

Are you ready to start the interview?

Steps:

1. Complete demographic information form by asking participant about each item.
2. Give the participant a copy of the measure.
3. Ask whether they would like to read the first page (instructions and example) themselves first or whether you should read for them.
4. Go through the example item and response choices and explain and allow them to practice on the example.
5. Explain to participant that you will be going through each statement (use term, *question* if that is more easily understandable) and asking them to explain how they are thinking about it aloud. If they get stuck with doing that, you will ask them questions to help them in that *thinking-aloud* process.
6. Tell participant that you will take them through an example to give them some practice before you start. Ask participant to: "Visualise the room where you sleep and think about how many windows there are in that room. As you are counting the windows, tell me what you are seeing and thinking about." Once done with this exercise, tell the participant that you want them to do the same with each question.
7. Start with each statement and use the answer sheet to make notes and write down participant's responses. Always start by asking the participant to think aloud, you can say: "I can see that you are thinking about your answer, would you please speak your thoughts aloud?" If they struggle, then use the verbal probes for each statement on the answer sheet. Also use a general probe, like: "You seemed to hesitate there, will you say something more about that?"
8. Once through all the questions on the answer sheet and reflected on the questions about the measure as a whole, complete the demographic information form.
9. Since we are done with most of this interview, how do you feel right now?
10. Also, give the participant R100 and ask them to sign the form for it.

Conclusion

I think this concludes this interview.

Is there anything that you would still like to say, or ask me?

By sharing your experiences and feelings, you have made it possible for me to have a better understanding of how well the questionnaire works for you and how I can improve it.

Thank you very much for your time and for taking part in this interview and my research project. I hope that it has also been a good experience for you.

Appendix C17: Demographic information sheet for cognitive interviews

DEMOGRAPHIC INFORMATION

1. AGE: _____

2. GENDER:

FEMALE 1	MALE 2

3. HOME LANGUAGE:

Afrikaans	1
English	2
IsiNdebele	3
IsiXhosa	4
IsiZulu	5
Sepedi	6
Sesotho	7
Setswana	8
SiSwati	9
Tshivenda	10
Xitsonga	11
Other (Specify)	12

4. MARITAL STATUS?

UNMARRIED 1	MARRIED / COMMITTED RELATIONSHIP 2	DIVORCED / SEPARATED 3	WIDOWED/WIDOWER 4

5. CURRENT EMPLOYMENT?

YES 1	NO 0

6. IF YES, TYPE OF EMPLOYMENT:

PERMANENT 1	SELF-EMPLOYED 2	PART-TIME EMPLOYED 3

7. CURRENT LIVING ARRANGEMENTS?

HOME 1	HOSPITAL / WARD 2	OTHER (Specify) 3

8. LEVEL OF EDUCATION

PRIMARY SCHOOL 1	HIGH SCHOOL 2	GRADE 12 / MATRIC 3	TERTIARY EDUCATION 4

9. AGE OF ONSET OF ILLNESS: _____

10. DIAGNOSIS?

Major Depressive Disorder	1
Schizophrenia	2
Schizoaffective Disorder	3
Bipolar Mood Disorder	4
Other (Specify)	5

11. PARTICIPANT'S LEVEL OF SATISFACTION WITH MIIMHR-SA:

NOT AT ALL 1	A LITTLE BIT 2	SOMEWHAT 3	QUITE A BIT 4	COMPLETELY 5

12. LENGTH OF MIMHR-SA:

TOO SHORT 1	SUFFICIENT 2	TOO LONG 3

13. UNDERSTANDABILITY OF ITEMS:

NOT AT ALL 1	A LITTLE BIT 2	SOMEWHAT 3	QUITE A BIT 4	COMPLETELY 5

14. ITEMS RELEVANT TO PARTICIPANT:

NOT AT ALL 1	A LITTLE BIT 2	SOMEWHAT 3	QUITE A BIT 4	COMPLETELY 5

FOR ADMINISTRATOR ONLY:

Length of time to complete recovery instrument: mins

Signature of administrator: _____

Date: _____

Appendix C18: Results from Matching of Randomly-ordered Items with Dimensions: Part 2

Of the 38 items that needed to be matched with their dimensions, eight items were matched as originally intended by all five service users. Another six items were matched as originally intended by 80% of the participants. Eight of the remaining 24 items received a matching as originally intended from 60% of the participants. The 16 remaining items received a matching of less than 60% as originally intended. Three items did not receive support from any of the participants for the dimension from which they were originally developed. Four items received 60% support from the participants for only one other dimension. The three items with no support for their dimension and the four items with 60% support for a single other dimension were reviewed. I noticed that two of the three items with no support for their original dimension were the same as two of the four items with 60% support for a single other dimension. I moved one of these two items, *I am doing positive things that I did before*, to the other dimension that received 60% support from the participants, namely *Moving positively forward*. I decided to retain the other of the two items, *I have purpose in my life*, in its original dimension and change the name of the first sub-dimension of that dimension to *Purpose* and not *Meaning*, as originally formulated. The latter change was also in line with feedback that I received throughout from service user participants, namely that purpose was a more apt and relatable word for them than meaning.

Appendix C19: Changes to Sub-dimensions of the Various Dimensions and Descriptions

I changed the sub-dimensions of the dimension, *(Re-)gaining of strengths*, to not include *Trust*. I moved *Trust* to the first dimension, *Relationships with Others*, so that it contained, *Connection*, *Support* and *Trust*. I then moved the item, *Other people trust me*, to the first dimension in line with this change. I further changed the content of the dimension, *Relating to the World*, to exclude *Insight,* as insight was identified as a controversial term by one of the international recovery academics, who felt quite strongly about it, during the Delphi expert consensus process and furthermore the dimension no longer contained an item relating to insight. I changed the description of the dimension, *Awareness of Difficulties*, from, *Acknowledgement of Difficulties, even impossibilities, faced by service users in their recovery process*, to, *Awareness by service users of difficulties faced in their recovery process*. This description is more in line with the spirit of recovery, which is positively focused. The description of the last dimension, *Clinical Understanding to Support Personal Recovery*, which had been contested by members of the Delphi panel already, was changed from, *The understanding of recovery by service users in a medical/clinical way*, to, *The importance of some clinical understanding for service users in their personal recovery process.* Although the distinction between clinical and personal recovery is very clear in some other, international settings, as discussed in section 2.1.1.1. in Chapter 2, I found that in the study setting, and given the context within, and the manner in which, mental health services are generally provided in South African settings, which is discussed in section 2.1.4. in Chapter 2, a clinical understanding of mental health was still important to some degree. Thus, by changing the description of the last dimension, I attempted to build a bridge between the international understanding of the distinction between clinical and personal recovery and the stronger reliance on clinical understanding as part of recovery in the study context. This might change as the field of recovery develops in future in South Africa.

Appendix C20: Details of changes to measure through various content validity stages

	Version I	Version II (Delphi panel)	Version III (Cognitive interviews)	Version IV	Version V (final)	Dimen-sion (final)
Introduction	This document contains a list of statements about how you might think and feel about yourself, your health, your life and your environment. By completing it you will help us to understand more about the process of your mental health recovery. The process of recovery is different for each person, so there are no right or wrong answers. By completing this document, we hope that the results will also help you to understand more about your own recovery process.	This is a list of statements about how you might think and feel about yourself, your health, your life and your environment. By completing it you will help us to understand more about the process of your mental health recovery. The process of recovery is different for each person, so there are no right or wrong answers. By completing this, we hope that the results will also help you to understand more about your own recovery process. Please use the results from this to discuss and/or plan your mental health recovery with your service provider or people close to you that you trust.	Mental health recovery is a process to: • Find meaning and hope in one's life • Find ways to re-connect with and • Contribute to one's community even if one is faced by mental health challenges. This is a list of statements about how you might think and feel about yourself, your health, your life and your environment. By completing it you will help us to understand more about the process of your mental health recovery. The process of recovery is different for each person, so there are no right or wrong answers. We hope that the results will also help you to understand more about your own recovery process. Please use the results to discuss and/or plan your mental health recovery with your service provider or people close to you that you trust.	No change	No change	N/A

	Version I	Version II	Version III	Version IV	Version V (final)	Dimen-sion (final)
Instructions	How much do you agree with each statement below? (Read and think about each statement carefully. Use the boxes on the right to mark the answer that best fits each statement for you. Only mark one box per statement. Please do not skip any statements.)	Same instructions as version I, but added: **Example statement:** *Through my mental health recovery, I have learnt about my strengths and weaknesses.*	Instructions: How much do you agree with each statement below? (Read and think about each statement carefully. Answer from your own perspective or point of view and from your own experience. Use the boxes on the right to mark the answer that best fits each statement for you. Only mark one box per statement. Please do not skip any statements.) **Go through the example below before you start:** (same example as in version II)	No change	No change	N/A

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimen-sion (final)**
Likert scale	1 = Not at all; 2 = A little bit; 3 = Somewhat; 4 = Quite a bit; 5 = Very much	Same response options as version I, except for 5, and added descriptions for each option: 1 = Not at all (*I don't agree with the statement in any way*); 2 = A little bit (*I agree with the statement to a small degree*); 3 = Somewhat (*I agree with the statement more than a little bit, but not yet a lot*); 4 = Quite a bit (*I agree with the statement a lot, but not completely*); 5 = Completely (*I agree with the statement in every way*)	No change	No change	No change	N/A
	Items					
1	I feel a (re-)connection with others	I feel a connection with others that support me.	No change	I feel connected to people who support me.	No change	1
2	I (can) communicate with others	I communicate with others.	I communicate with other people in general.	In general, I communicate with people.	No change	1
3	I (can) interact with others	I interact with others.	- [a]	-	-	-

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimen-sion (final)**
4	I (can) get along with others	I get along with others.	I get along with other people in general.	In general, I get along with people.	No change	1
5	I feel a (re-)connection to my community	I feel a positive connection to my community.	No change	I feel positively connected to a community.	No change	1
6	I feel like a person who is part of my community	I feel like I am part of my community.	I feel like a member OR I am part of OR I belong in my community.	I feel part of a community.	No change	1
7	I feel that I am supported	-	-	-	-	-
8	I feel that I am supported by others	I feel that I am supported, emotionally, financially or otherwise, by others.	I feel that I am supported (for example emotionally, financially or otherwise) by others.	I feel supported by others.	No change	1
9	I feel understood (by others)	-	-	-	-	-
10	I provide support to others	I support others, either emotionally, financially or otherwise.	I support others (for example emotionally, financially or otherwise).	I support others.	No change	1

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimen-sion (final)**
11	I feel that I inspire others	-	-	-	-	-
12	I feel that I can be a role model to others	I feel that I am a role model to others because of my mental health recovery.	I feel that others can look up to me because of my mental health recovery.	I feel that people can look up to me because of my mental health recovery.	No change	1
13	I feel like I have adjusted to my mental illness	-	-	-		
14	I feel like I have adjusted to my situation	I feel like I have adjusted to my mental health situation.	I feel like I have adjusted to OR accepted my mental health situation.	I have adjusted to my mental health situation.	No change	2
15	I feel like I am making progress	I feel like I am making progress with my mental health recovery.	No change	I am making progress with my mental health recovery.	No change	2

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimen-sion (final)**
16	I feel like I am moving forward with my illness	I feel like I am moving forward with how I live with my mental health recovery.	-	-	-	-
17	I am thinking in a positive way	I am thinking in a positive way about my mental health.	No change	I think in a positive way about my mental health.	No change	2
18	I feel like I can go on	-	-	-	-	-
19	I can take small steps, into the future	I set goals for my future.	-	-	-	-
20	I can make plans (again) for the future	I make plans for my future.	No change	No change	No change	2
21	I feel a (re-)connection with myself	I understand myself better through my mental health recovery.	No change	No change	No change	3
22	I feel like I am loved	-	-	-	-	-
23	I have a role to play as a person	I feel I have a place in my community.	-	-	-	-
24	I have a routine	I have a routine for my daily tasks.	No change	No change	No change	3

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimen-sion (final)**
25	I feel like I have a new life (ahead of me)	I feel like I have a new life ahead of me. (Moved from dimension 3 to dimension 2)	I feel like I have a new life ahead of me because of my mental health recovery. (Moved from dimension 3 to dimension 2)	No change	No change	2
26	I am taking part in things that I did before	I am doing things (like hobbies, interests, or social activities) that I did before.	I am doing positive things (for example hobbies, interests, or social activities) that I did before.	I am doing positive things that I did before.	No change to wording. (Moved from dim 3 to dim 2)	2
27	I am even doing more things than I did before	I am doing new things.	No change	No change	No change	3
28	I feel again like the person I was before my mental illness	-	-	-	-	-
29	I have meaning in my life	Same as in version I	-	-	-	-
30	I have purpose in my life	Same as in version I	Same as version I	Same as version I	Same as version I	4
31	My faith/belief/religion/prayer helps me	Faith/belief/religion/prayer/spirituality helps me.	No change	No change	No change	4

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimen-sion (final)**
32	My faith/belief/religion/prayer helps me to not feel alone	-	-	-	-	-
33	I can live a normal life	-	-	-	-	-
34	I can contribute to society	I feel that I contribute to society in positive ways.	No change	I contribute to society in positive ways.	No change	4
35	I can acknowledge that I have a mental illness if I want to	-	-	-	-	-
36	I accept my mental illness	-	-	-	-	-
37	I know myself, who I am	Through my mental health recovery, I have learnt about myself.	No change	-	-	-

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimen-sion (final)**
38	I know about my mental illness	I have information about my mental illness. (Moved from dimension 4 to dimension 6)	No change	I have information about my mental health. (Moved from dimension 4 to dimension 7)	No change	7
39	I am able to identify symptoms early, that can make me sick again	I am able to identify triggers early, that can make me sick again. (Moved from dimension 4 to dimension 7)	No change	No change	No change	7
40	Having a job is important to me	-	-	-		-
41	Earning an income is important to me	Earning an income is important to me.	Earning an income is important to my mental health recovery.	No change	No change	5
42	I have skills that can help me in my life	I have skills that can help me live my life positively.	No change	I have skills that help me live my life positively.	No change	5

	Version I	Version II	Version III	Version IV	Version V (final)	Dimen-sion (final)
43	I have skills that can help me with my illness	I have skills that can help me live positively with my mental health recovery.	-	-	-	-
44	I am responsible for myself	I take responsibility for myself.	I take responsibility for myself OR my own life.	I take responsibility for my own life.	No change	5
45	I can make decisions for myself	I make decisions for myself.	I make decisions about my own life.	No change	No change	5
46	I feel that I am allowed to make decisions for myself	I have good judgement to decide what's good or bad for me.	No change	No change	No change	5
47	I can take initiative to do things	I decide for myself to do things.	-	-	-	-
48	I feel like I am trusted by others	I feel like other people trust me.	No change	Other people trust me.	No change to wording. (Moved from dim 5 to dim 1)	1
49	I can do things that others can do	I feel like I am just as able as other people to do things.	-	-	-	-

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimen-sion (final)**
50	I feel like I can cope with my mental illness	I feel like I can manage with my mental health recovery.	I feel like I am in control of my mental health recovery.	I feel I'm in control of my mental health recovery.	No change	5
51	I know how to deal with my stress	I feel that I am able to deal with my stress.	No change	I am able to deal with my stress.	No change	6
52	Sometimes I feel like I am recovering and other times I don't feel like I am recovering	Even though recovery has ups and downs, overall I feel like I am moving in a positive direction. (moved from dimension 6 to dimension 2)	No change	No change	No change	2
53	I know my limitations	I know the challenges of my mental health recovery.	I am aware of my own challenges with mental health recovery.	No change	No change	6
54	I feel like recovery is difficult	Sometimes I feel like mental health recovery is difficult.	No change	No change	No change	6
55	My environment makes my recovery difficult	Sometimes my environment (like family/friends/work/where I live) makes my recovery difficult.	Sometimes my environment (for example family/friends/work/where I live) makes my recovery difficult.	Sometimes my environment makes my recovery difficult.	No change	6

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimen-sion (final)**
56	I feel better	I feel better than I did before.	No change	I feel better than I did before. If second or further time completing the questionnaire, answer the following: I feel better than the previous time I completed this questionnaire.	No change	7
57	I feel healed	-	-	-	-	-
58	I feel well	-	-	-	-	-
59	I feel it is important for me to take my medication	If I have to take medicine, I feel it is important that I take it.	-	-	-	-

	Version I	**Version II**	**Version III**	**Version IV**	**Version V (final)**	**Dimension (final)**
60	If I take my pills (medication), I will recover	I feel that it will help me to recover if I take my medicine.	No change	It will help me to recover if I take my medicine.	No change	7
61	If I have no symptoms, I am recovering from my mental illness	I can still be recovering if I have symptoms.	I can be recovering if I still have some symptoms.	No change	No change	7
62	If I still take medication, I am not recovering from my mental illness	-	-	-	-	-
63	When I get discharged, I don't have a mental illness anymore	Being discharged means I am mentally healthy.	No change	Being discharged means I am mentally healthy.	No change	7
	63 items; 7 dimensions	48 items; 7 dimensions	39 items; 7 dimensions	38 items; 7 dimensions	38 items	7 dimen-sions

Note. [a] The use of "-" means exclusion of the item from further versions of the measure.

Appendix C21: Final version of Measure of Individual Mental Health Recovery for a South African context (MIMHR-SA)

Name: _____ Date: _____ Start time: _____ End time: _____

MEASURE OF INDIVIDUAL MENTAL HEALTH RECOVERY FOR A SOUTH AFRICAN CONTEXT (MIMHR-SA)

Mental health recovery is a process to:

- Find meaning and hope in one's life
- Find ways to re-connect with and
- Contribute to one's community even if one is faced by mental health challenges.

This is a list of statements about how you might think and feel about yourself, your health, your life and your environment. By completing it you will help us to understand more about the process of your mental health recovery. The process of recovery is different for each person, so there are no right or wrong answers. We hope that the results will also help you to understand more about your own recovery process. Please use the results to discuss and/or plan your mental health recovery with your service provider or people close to you that you trust.

Instructions: How much do you agree with each statement below?
(Read and think about each statement carefully. Answer from your own perspective or point of view and from your own experience. Use the boxes on the right to mark the answer that best fits each statement for you. Only mark one box per statement. Please do not skip any statements.)

Go through the example below before you start:

		"I don't agree with the statement in any way."	"I agree with the statement to a small degree."	"I agree with the statement more than a little bit, but not yet a lot."	"I agree with the statement a lot, but not completely."	"I agree with the statement in every way."
		Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Completely**
	Through my mental health recovery, I have learnt about my strengths and weaknesses.	1	2	3	4	5

		"I don't agree with the statement in any way."	"I agree with the statement to a small degree."	"I agree with the statement more than a little bit, but not yet a lot."	"I agree with the statement a lot, but not completely."	"I agree with the statement in every way."
		Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Completely**
1	I feel connected to people who support me.	1	2	3	4	5
2	In general, I communicate with people.	1	2	3	4	5
3	In general, I get along with people.	1	2	3	4	5
4	I feel positively connected to a community.	1	2	3	4	5
5	I feel part of a community.	1	2	3	4	5
6	I feel supported by others.	1	2	3	4	5
7	I support others.	1	2	3	4	5
8	I feel that people can look up to me because of my mental health recovery.	1	2	3	4	5
9	Other people trust me.	1	2	3	4	5
10	I have adjusted to my mental health situation.	1	2	3	4	5
11	I am making progress with my mental health recovery.	1	2	3	4	5
12	I think in a positive way about my mental health.	1	2	3	4	5
13	I make plans for my future.	1	2	3	4	5
14	I have a new life ahead of me because of my mental health recovery.	1	2	3	4	5
15	Even though recovery has ups and downs, overall I am moving in a positive direction.	1	2	3	4	5
16	I am doing positive things that I did before.	1	2	3	4	5
17	I understand myself better through my mental health recovery.	1	2	3	4	5
18	I have a routine for my daily tasks.	1	2	3	4	5
19	I am doing new things.	1	2	3	4	5
20	I have purpose in my life.	1	2	3	4	5
21	Faith/belief/religion/prayer/spirituality helps me.	1	2	3	4	5
22	I contribute to society in positive ways.	1	2	3	4	5
23	Earning an income is important to my mental health recovery.	1	2	3	4	5

		"I don't agree with the statement in any way."	"I agree with the statement to a small degree."	"I agree with the statement more than a little bit, but not yet a lot."	"I agree with the statement a lot, but not completely."	"I agree with the statement in every way."
		Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Completely**
24	I have skills that help me live my life positively.	1	2	3	4	5
25	I take responsibility for my own life.	1	2	3	4	5
26	I make decisions about my own life.	1	2	3	4	5
27	I have good judgement to decide what's good or bad for me.	1	2	3	4	5
28	I feel I'm in control of my mental health recovery.	1	2	3	4	5
29	I am able to deal with my stress.	1	2	3	4	5
30	I am aware of my own challenges with mental health recovery.	1	2	3	4	5
31	Sometimes I feel like mental health recovery is difficult.	1	2	3	4	5
32	Sometimes my environment makes my recovery difficult.	1	2	3	4	5
33	I feel better than I did before. If second or further time completing the questionnaire, answer the following: I feel better than the previous time I completed this questionnaire.	1	2	3	4	5
34	It will help me to recover if I take my medicine.	1	2	3	4	5
35	I can be recovering if I still have some symptoms.	1	2	3	4	5
36	Being discharged means I am mentally healthy.	1	2	3	4	5
37	I have information about my mental health.	1	2	3	4	5
38	I am able to identify triggers early, that can make me sick again.	1	2	3	4	5

Thank you very much for your answers and contribution.

Appendix C22: Stellenbosch University's Research Ethics Committee: Human Research (Humanities) approval and extensions

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

NOTICE OF APPROVAL

REC Humanities New Application Form

20 January 2018

Project number: 1711

Project Title: The development of a contextually-appropriate measure of individual recovery for mental health service users in the South African context

Dear Ms. Anneliese De Wet

Your response to stipulations submitted on 20 December 2017 was reviewed and approved by the REC: Humanities.

Please note the following for your approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
30 November 2017	29 November 2018

GENERAL COMMENTS:

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.

Please use your SU project number (1711) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

Included Documents:

Document Type	File Name	Date	Version
Research Protocol/Proposal	2017-09-25_A de Wet_Proposal_development of a recovery measure_final	25/09/2017	Final
Non-disclosure agreement	2017-10-17 Declaration of confidentiality_research assistant	23/10/2017	1
Request for permission	2017-10-31 Part completed DoH Ethics application	31/10/2017	1
Request for permission	2017-10-31 Screen shot of ADW profile on NHRD website	31/10/2017	1
Request for permission	Explanation to REC re institutional permission	31/10/2017	1
Data collection tool	Explanation to REC re survey_questionnaire_test	31/10/2017	1
Proof of permission	Explanation to REC re proof of permission to use existing data collection tool	31/10/2017	1

Default	Graphic representation of phases of study	31/10/2017	1
Recruitment material	Flyer_Ad_recovery instrument administration	31/10/2017	1
Informed Consent Form	2017-12-19 ICF_SUN REC_service user_English	19/12/2017	2
Informed Consent Form	2017-12-19 ICF_SUN_REC_carers_English	19/12/2017	2
Informed Consent Form	2017-12-19 ICF_SUN_REC_serviceprovider_English	19/12/2017	2
Informed Consent Form	2017-12-19 ICF_SUN_REC_prof experts_English	19/12/2017	2
Data collection tool	2017-12-19 Interview schedule – carers_English	19/12/2017	2
Data collection tool	2017-12-19 Interview schedule – service providers_English	19/12/2017	2
Data collection tool	2017-12-19 Interview schedule_service user_English	19/12/2017	2
Data collection tool	2017-12-19 Focus group guide_ for all participants_English	19/12/2017	2
Data collection tool	2017-12-19 Consent process for focus groups	19/12/2017	2
Data collection tool	2017-12-19 Consent process for interviews	19/12/2017	2
Request for permission	2017-12-19 Email thread to Stikland Hospital regarding study to obtain permission in principle	19/12/2017	2
Request for permission	2017-12-19 Email thread to Valkenberg Hospital regarding study to obtain permission in principle	19/12/2017	2
Request for permission	2017-12-19 Emails to Lentegeur Hospital regarding study to discuss study and possibilities	19/12/2017	2
Default	2017-12-20 Response to REC stipulations	20/12/2017	1

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Human Research (Humanities)

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.
The Research Ethics Committee: Humanities complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.

Investigator Responsibilities

Protection of Human Research Participants

Some of the general responsibilities investigators have when conducting research involving human participants are listed below:

1.Conducting the Research. You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research. You must also ensure that the research is conducted within the standards of your field of research.

2.Participant Enrollment. You may not recruit or enroll participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use.

3.Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the REC-approved consent documents/process, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (5) years.

4.Continuing Review. The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period.** Prior to the date on which the REC approval of the research expires, **it is your responsibility to submit the progress report in a timely fashion to ensure a lapse in REC approval does not occur.** If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.

5.Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the REC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written REC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

6.Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research related injuries, occurring at this institution or at other performance sites must be reported to Malene Fouche within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Research Ethics Committee Standard Operating Procedures. All reportable events should be submitted to the REC using the Serious Adverse Event Report Form.

7.Research Record Keeping. You must keep the following research related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the REC

8.Provision of Counselling or emergency support. When a dedicated counsellor or psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.

9.Final reports. When you have completed (no further participant enrollment, interactions or interventions) or stopped work on your research, you must submit a Final Report to the REC.

10.On-Site Evaluations, Inspections, or Audits. If you are notified that your research will be reviewed or audited by the sponsor or any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

NOTICE OF APPROVAL

REC Humanities Progress report form

5 November 2018

Project number: 1711

Project Title: The development of a contextually-appropriate measure of individual recovery for mental health service users in the South African context

Dear Miss Anneliese De Wet

Your REC Humanities Progress report form submitted on 12 September 2018 was reviewed and approved by the REC: Humanities.

Please note the following for your approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
5 November 2018	4 November 2019

GENERAL COMMENTS:

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.

Please use your SU project number (1711) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

Included Documents:

Document Type	File Name	Date	Version
Research Protocol/Proposal	2017-09-25_A de Wet_Proposal_development of a recovery measure_final	25/09/2017	V1
Informed Consent Form	2017-12-19 ICF_SUN REC_service user_English	19/12/2017	V1
Informed Consent Form	2017-12-19 ICF_SUN_REC_carers_English	19/12/2017	V1
Informed Consent Form	2017-12-19 ICF_SUN_REC_prof experts_English	19/12/2017	V1
Informed Consent Form	2017-12-19 ICF_SUN_REC_serviceprovider_English	19/12/2017	V1
Default	2018-08-16 Application for retrospective approval of dissertation by publication_final	16/08/2018	V1

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Human Research (Humanities)

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.
The Research Ethics Committee: Humanities complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.

Investigator Responsibilities

Protection of Human Research Participants

Some of the general responsibilities investigators have when conducting research involving human participants are listed below:

1.Conducting the Research. You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research. You must also ensure that the research is conducted within the standards of your field of research.

2.Participant Enrollment. You may not recruit or enroll participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use.

3.Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the REC-approved consent documents/process, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (5) years.

4.Continuing Review. The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period.** Prior to the date on which the REC approval of the research expires, **it is your responsibility to submit the progress report in a timely fashion to ensure a lapse in REC approval does not occur.** If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.

5.Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the REC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written REC review and approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

6.Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research related injuries, occurring at this institution or at other performance sites must be reported to Malene Fouche within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch University Research Ethics Committee Standard Operating Procedures. All reportable events should be submitted to the REC using the Serious Adverse Event Report Form.

7.Research Record Keeping. You must keep the following research related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the REC

8.Provision of Counselling or emergency support. When a dedicated counsellor or psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.

9.Final reports. When you have completed (no further participant enrollment, interactions or interventions) or stopped work on your research, you must submit a Final Report to the REC.

10.On-Site Evaluations, Inspections, or Audits. If you are notified that your research will be reviewed or audited by the sponsor or any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

NOTICE OF APPROVAL

REC: SBER - Annual Progress/ Final Report

24 October 2019

Project number: 1711

Project Title: The development of a contextually-appropriate measure of individual recovery for mental health service users in the South African context

Dear Miss Anneliese De Wet

Your REC: SBER - Annual Progress Report submitted on 13 September 2019 was reviewed and approved by the REC: Humanities.

Please note the following for your approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
4 November 2019	3 November 2020

GENERAL COMMENTS:

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.

Please use your SU project number (1711) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

Included Documents:

Document Type	File Name	Date	Version
Research Protocol/Proposal	2017-09-25_A de Wet_Proposal_development of a recovery measure_final	25/09/2017	v.1
Informed Consent Form	2017-12-19 ICF_SUN REC_service user_English	19/12/2017	v.1
Informed Consent Form	2017-12-19 ICF_SUN REC_service user_FGD_English	19/12/2017	v.1
Informed Consent Form	2017-12-19 ICF_SUN_REC_carers_English	19/12/2017	v.1
Informed Consent Form	2017-12-19 ICF_SUN_REC_carers_FGDs_English	19/12/2017	v.1
Informed Consent Form	2017-12-19 ICF_SUN_REC_prof experts_English	19/12/2017	v.1
Informed Consent Form	2017-12-19 ICF_SUN_REC_serviceprovider_English	19/12/2017	v.1
Informed Consent Form	2017-12-19 ICF_SUN_REC_serviceprovider_FGDs_English	19/12/2017	v.1
Default	2018-08-16 Application for retrospective approval of dissertation by publication_final	16/08/2018	v.1

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Human Research (Humanities)

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.
The Research Ethics Committee: Humanities complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.

Investigator Responsibilities

Protection of Human Research Participants

Some of the general responsibilities investigators have when conducting research involving human participants are listed below:

1.Conducting the Research. You are responsible for making sure that the research is conducted according to the REC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research. You must also ensure that the research is conducted within the standards of your field of research.

2.Participant Enrollment. You may not recruit or enroll participants prior to the REC approval date or after the expiration date of REC approval. All recruitment materials for any form of media must be approved by the REC prior to their use.

3.Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the REC-approved consent documents/process, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least five (5) years.

4.Continuing Review. The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period.** Prior to the date on which the REC approval of the research expires, **it is your responsibility to submit the progress report in a timely fashion to ensure a lapse in REC approval does not occur.** If REC approval of your research lapses, you must stop new participant enrollment, and contact the REC office immediately.

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9.Final reports. When you have completed (no further participant enrollment, interactions or interventions) or stopped work on your research, you must submit a Final Report to the REC.

10.On-Site Evaluations, Inspections, or Audits. If you are notified that your research will be reviewed or audited by the sponsor or any other external agency or any internal group, you must inform the REC immediately of the impending audit/evaluation.

Appendix C23: Western Cape Department of Health approval and extensions

Western Cape Government
Health

Health Impact Assessment
Health Research Sub-Directorate
Health.Research@westerncape.gov.za
Tel: +27 21 483 0866: fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_201801_032
ENQUIRIES: Dr Sabela Petros

Stellenbosch University

Faculty of Medicine and Health Sciences

Francie VAn Zijl drive

Tygerberg Hospital

Cape Town

7505

For attention: Ms Anneliese De Wet, Dr Chrisma Pretorius

Re: The development of a contextually-appropriate measure of individual recovery for mental health service users in the South African context.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact following people to assist you with any further enquiries in accessing the following sites:

Lenteguer Hospital	**Ms Nadine Jacobs**	**021 370 1105**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR J EVANS

ACTING DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 06/04/18

Health Impact Assessment
Health Research Sub-Directorate
Health.Research@westerncape.gov.za
Tel: +27 21 483 0866: fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_201801_032
ENQUIRIES: Dr Sabela Petros

Stellenbosch University

Faculty of Medicine and Health Sciences

Francie VAn Zijl drive

Tygerberg Hospital

Cape Town

7505

For attention: Ms Anneliese De Wet, Dr Chrisma Pretorius

Re: The development of a contextually-appropriate measure of individual recovery for mental health service users in the South African context.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact following people to assist you with any further enquiries in accessing the following sites:

Stikland Hospital	**Dr Liezle Koen**	**021 940 4570**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR G DENICKER

ACTING DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 28-03-2018

Health Impact Assessment
Health Research Sub-Directorate
Health.Research@westerncape.gov.za
Tel: +27 21 483 0866: fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_201801_032
ENQUIRIES: Dr Sabela Petros

Stellenbosch University

Faculty of Medicine and Health Sciences

Francie VAn Zijl drive

Tygerberg Hospital

Cape Town

7505

For attention: Ms Anneliese De Wet, Dr Chrisma Pretorius

Re: The development of a contextually-appropriate measure of individual recovery for mental health service users in the South African context.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact following people to assist you with any further enquiries in accessing the following sites:

Valkenberg Hospital	**Prof Sean Kaliski**	**021 826 5865**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

A HAWKRIDGE.

DR A HAWKRIDGE

DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 22/3/2018

Western Cape Government
Health

Health Impact Assessment
Health Research Sub-Directorate
Health.Research@westerncape.gov.za
Tel: +27 21 483 0866: fax: +27 21 483 9895
5th Floor, Norton Rose House, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_201801_032
ENQUIRIES: Dr Sabela Petros

Stellenbosch University

Faculty of Medicine and Health Sciences

Francie VAn Zijl drive

Tygerberg Hospital

Cape Town

7505

For attention: Ms Anneliese De Wet, Dr Chrisma Pretorius

Re: The development of a contextually-appropriate measure of individual recovery for mental health service users in the South African context.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact following people to assist you with any further enquiries in accessing the following sites:

Lenteguer Hospital	**Ms Nadine Jacobs**	**021 370 1105**
Stikland Hospital	**Dr Liezle Koen**	**021 940 4570**
Valkenberg Hospital	**Prof Sean Kaliski**	**021 826 5865**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. By being granted access to provincial health facilities, you are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within

six months of completion of your project. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR M MOODLEY

DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 05-02-2019

Western Cape Government
Health

HEALTH RESEARCH
sabela.petros@westerncape.gov.za
tel: +27 21 483 0866: fax: +27 21 483 9895
5th Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_201801_032

ENQUIRIES: Sabela Petros

RE: REQUEST FOR CONTINUATION OF PERMISSION TO CONDUCT RESEARCH IN THE WESTERN CAPE PROVINCE DEPARTMENT OF HEALTH FACILITIES.

Dear Mej De Wet

Thank you for making enquiries about the continuation of your research project entitled "*The development of a contextually-appropriate measure of individual recovery for mental health service users in the South African context*". The Department is pleased to inform you that your study may continue at the following facilities:

1.	Valkenberg hospital,	Contact person	Ms Estelle Malgas	021-826 5805
2.	Lentegeur Hospital,	Contact person	Ms **Nadine Jacobs**	021-370 1105
3.	Stikland Psychiatric Hospitals.	Contact person	Prof Koen Liezle :	021-940 4570

We hope your study will assist us in understanding and broadening existing knowledge on the challenge of mental problems and provide us with useful information to apply in our services.

Yours sincerely

Dr M Moodley
DIRECTOR: HEALTH IMPACT ASSESSMENT (HIA)
DATE:

Dr Melvin Moodley
Director: Health Impact Assessment
21 NOV 2019

Appendix C24: Consent process document: Interviews

Introduction

Good day, thank you for being willing so far to participate in this interview. My name is Anneliese de Wet. I am busy studying for a doctoral degree in psychology at Stellenbosch University. As part of this, I have to do research and write down what I find in a thesis or some articles. The information that I will collect from you in this interview will be used as part of my research. I will need your consent to do this. I will explain this to you in more detail shortly.

But first I want to explain a bit about my study to you, so you can understand what it is about and make a decision for yourself whether you want to take part in it. My study is about mental health recovery. Recovery is a process to:

- Find meaning and hope in your life
- Find ways to re-connect with and
- Contribute to your community even if you face mental health challenges.

My study has two parts to it.

Part 1:

The first part is to understand your own, your family members' / loved ones' and the persons who work with your family member / loved one at the hospital:

1. perceptions and understanding of recovery, and
2. what makes recovery work or not.

I want to know these things, to determine what recovery means where you and your family member / loved one lives and also how that is different from how other people in other countries understand recovery.

I plan to ask you and other people about these things in individual interviews, such as this, and later on in groups.

After I have received the information from everyone, in the interviews and groups, I will look at it and work with it to understand what recovery means here where you live.

Part 2:

The second part of the study will be to create a list of questions that are about where someone is in their recovery process and to ask some of you and some academic and professional people to help me work out if I am on the right track with the questions and then ask people who use the services at the hospital to answer these questions for me. This will help me to create a

document in the end with all the right questions about where someone is in their recovery process, that will work for where you and your family member / loved one lives and that can be used by people who are interested in recovery.

I would like to record the interviews with your permission, to write down every word from the recordings and then try to understand what you and the other participants have said. I will then write about it in my thesis and in articles.

Do you understand what I have said so far?

[Allow the participant time to answer; if yes, move on to the next question; if no, ask what it is that the participant does not understand and answer all the participant's questions in an unhurried way until the participant is able to answer yes, when asked again.]

Before I ask you to consent to this interview, it is important that you understand that you are completely free to choose to take part in this research or not. If you choose not to take part, it will not affect your or your family member's / loved one's participation in other activities or services at the hospital. Also, once you have chosen to take part, you are also free to choose to not take part anymore at any time before, during or after the interviews. Any information that I would have already received from you then will not be used in the research.

Also, I will not reveal your name to anyone except my lecturer. So, no-one except me and my lecturer will know that it was you who said the things you did. I will also not share any part of what you have told me with anyone else, except my lecturer, before giving you another name and take out other details that might identify you so people who read or hear about it cannot easily identify you. Once I have done that, I will be able to share what you have told me with those persons who will evaluate my thesis, professional persons at the hospitals and through publication in professional journals.

If you feel uncomfortable at any stage during or directly after the interviews, you are welcome to tell me and I will stop the interview, as the case may be, and ensure that a professional person is available to talk to you about what is bothering you. I also need to inform you that you will not receive any money or anything else for participating in this research project except a contribution toward your travelling costs, if applicable.

Do you understand this?

[Allow the participant time to answer; if yes, move on to the next question; if no, ask what it is that the participant does not understand and answer all the participant's questions in an unhurried way until the participant is able to answer yes, when asked again.]

Do you consent to all these things that I have explained to you?

[Allow the participant time to answer; if yes, move on to the next question; if no, thank him or her for their time and wish them all the best in the future.]

Could you please sign this consent form?

[Allow the participant time to answer; If yes, hand the consent form to the participant for signature. Allow the participant time to read the consent form and sign it, or ask questions. Answer these questions and ask the participant again if he or she would sign the consent form;

If the participant answers no at any stage, thank him or her for their time and wish them all the best in the future.]

Once the consent form has been signed and handed back:

If you wish, I can also report back to you on the results of my research. Would you like me to do that?

[Make a note of the participant's answer on the consent form]

The interview should take about 45 minutes to an hour. Will this be in order?

[Bear in mind that this might have been communicated to the participant already upon making the appointment; Allow the participant time to answer; if yes, move on to the next question; if no, ask how much time the participant has available and decide whether it would make sense to continue with the interview or reschedule it.]

Appendix C25: Consent process document: Focus groups

Introduction

Good day, thank you for being willing so far to participate in this focus group discussion. For some of you this is the second time taking part in my study. Thank you. Others of you are new to this study and I equally appreciate your time and effort to be here. For those of you who don't yet know, my name is Anneliese de Wet and this is my research assistant, Elna Sutherland, who will be helping me during this focus group discussion. I am busy studying for a doctoral degree in psychology at Stellenbosch University. As part of this, I have to do research and write down what I find in a thesis or some articles. The information that I will collect from you in this focus group discussion will be used as part of my research. I will need your consent to do this. I will explain this to you in more detail shortly.

But first I want to briefly explain or recap a bit again about my study, so you can think about it and decide whether you want to take part in it (again). My study is about mental health recovery. Perhaps you know this already, but if you don't recovery is a process to:

- Find meaning and hope in your life
- Find ways to re-connect with and
- Contribute to your community even if you face mental health challenges.

My study has two parts to it.

Part 1:

The first part is to understand perceptions and understanding of recovery what makes recovery work or not to determine what recovery means in this context. This focus group forms part of this first part of the study.

Part 2:

The second part of the study will be to create a questionnaire to determine where someone is in their recovery process.

The idea with the focus group discussion is to broadly revisit the topics that were discussed during the interviews (that some of you might have been part of), give you an idea of what we found in the interviews, get an idea of how the group comes to understand these topics and whether the group agrees with my understanding of what participants shared in the interviews. The focus groups are very important to validate the interview data.

I would like to record the focus group discussion with your permission, to write down every word from the recordings / transcribe them and then make sense of what you and the other participants have said. I will then write about it in my thesis and in articles.

Do you understand what I have said so far?

[Allow the participants each time to answer; if yes, move on to the next question; if no, ask what it is that the participants do not understand and answer the participants' questions in way until the participants are all able to answer yes, when asked again.]

Before I ask you to consent to this focus group, it is important that you understand that you are completely free to choose to take part in this research or not. If you choose not to take part, it will not affect the services you or your family member / loved one receives or your position at the hospital. Also, once you have chosen to take part, you are also free to choose to not take part anymore at any time before, during or after the focus group. Any information that I would have already received from you then will not be used in the research. I will take out your answers from the transcription of the recording today.

Also, I will not reveal your names to anyone except my lecturer. So, no-one outside this group, except me and my lecturer will know that it was you who shared the things you did. I will also not share any part of what you have told us here today with anyone else, except my lecturer, before giving you another name / pseudonym and removing identifying markers, so people who read or hear about it cannot easily identify you. Once I have done that, I will be able to share what you have told me with those persons who will evaluate my thesis, professional persons at the hospitals and through publication in professional journals.

If you feel uncomfortable at any stage during or directly after the focus group, you are welcome to tell me and I will pause the focus group and ensure that a professional person is available to talk to you separately about what is bothering you. I also need to inform you that you will not receive any money or anything else for participating in this research project except a contribution toward your travelling costs, if applicable.

While we are busy with the focus group I would like to ask you to observe the following:

1. Please be **respectful to each person** in the room and their views. We will not all agree all of the time, so it is important that we allow the space for others to differ in their opinions from us without feeling that we judge or reject them.
2. Please **do not speak to anyone outside of the focus group** about what has been said in the focus group. Participants will be sharing their opinions and experiences and might expect you to keep that confidential. If participants are sure of the

confidentiality of the information they share, they will feel free to share and this will help me to get the best understanding from the focus group.

3. Please make sure that **only one person speaks at a time**. Let the person who is speaking make their point without interrupting them or speaking while they are speaking. If I feel that one person is dominating the discussion, I might ask that person kindly to finish the thought that they are busy with and allow others to contribute too. I will try my best to give everyone the opportunity to contribute.
4. Try to **keep sounds**, other than voices, **to the minimum**. Moving papers / plastic / chairs, for example gets picked up by the audio recorder and comes out loudly when I listen to it again and try to make out the voices. Sometimes it can overshadow the voices and I will not be able to make out what you have said and might miss a really important contribution that you have made. That would be a pity.
5. If someone decides that they no longer want to take part in the focus group or feels unwell while the focus group is still underway, I will pause the discussion and see that person out. Please **refrain from continuing with the discussion while I am out** – I don't want to miss out on what you say!

Do all understand this?

[Allow the participants time to answer; if yes, move on to the next question; if no, ask what it is that the participants do not understand and answer all the participants' questions in a way until the participants are all able to answer yes, when asked again.]

Do you consent to all these things that I have explained to you?

[Allow the participants time to answer; if yes, move on to the next question; if no, thank those participants for their time and wish them all the best in the future. See them out of the room.]

Could you please sign this consent form?

[Allow the participants time to answer; If yes, hand the consent form to the participants for signature. Allow the participants time to read the consent form and sign it, or ask questions. Answer these questions and ask the participants again if they would sign the consent form;

If the participants answer no at any stage, thank those participants for their time and wish them all the best in the future. See them out of the room.]

Once the consent form has been signed and handed back:

If you wish, I can also report back to you on the results of my research. Would you like me to do that?

[Make a note of the participants' answer on the consent form]

The focus group should take about 45 – 90 minutes.

[Bear in mind that this would have been communicated to the participants already upon making the arrangements.]

Of course, once again, you are free to leave the focus group at any time, should you not wish to continue with it.

Appendix C26: Informed consent form for service users

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

You are invited to take part in a study conducted by Anneliese de Wet, from the Psychology Department at Stellenbosch University. You were approached as a possible participant because you are:

- a **service user** (patient) at Lentegeur, Stikland or Valkenberg Hospitals in the Western Cape of South Africa.

1. PURPOSE OF THE STUDY

This study is about mental health recovery.

Recovery is a process to:

- Find meaning and hope in one's life
- Find ways to re-connect with and
- Contribute to one's community even if one is faced by mental health challenges.

The study has two parts to it.

Part 1:

The first part will involve service users, service providers and carers to work out what recovery is and means to these participants and what they think makes recovery work or not.

I want to know these things, to determine what recovery means in the Western Cape and how it is different from how other people in other countries understand recovery.

I plan to ask the participants about these things in individual interviews and focus groups.

Part 2:

The second part of the study will be to create a list of questions from which one will be able to tell where someone is in their recovery process and to involve service users, service providers, carers, psychometrists and academic people who study recovery in South Africa and overseas to help me work out if I am on the right track with these questions. Once I have worked out what the right questions are, I will ask service users at the hospital to answer these questions for me. This will help me to create a document (questionnaire) in the end with all the right questions about where someone is in their recovery process, specifically for how recovery is understood in the Western Cape and that can be used by those who are interested in recovery.

2. WHAT WILL BE ASKED OF ME?

If you agree to take part in this study, you will be asked to either:

- take part in an interview (45 – 60 minutes);
- a focus group discussion (45 - 90 minutes);
- working out the right questions for the document (questionnaire) about recovery, or
- to answer the questionnaire.

If you take part in an interview, you might be asked to take part in a focus group discussion later, but you will have the choice to decide whether you want to take part in the focus group or not. The interviews, focus groups and deciding on questions by service users, service providers and carers will take place at either Lentegeur, Stikland or Valkenberg Hospitals at the convenience of the participants involved and will be held in a room at the hospital where the door can be closed to ensure a measure of privacy for participant(s). The other activities for other participants will take place by email.

3. POSSIBLE RISKS AND DISCOMFORTS

It is possible that you might experience feelings of discomfort when talking about mental health recovery in the interviews or focus groups. However, I will ensure that a professional person is available to talk to you about these feelings, should you wish to do so. Please let me know at any point during the interviews or focus groups if you should feel such discomfort and I will pause or stop and first help you to get to the professional person so you can talk to them. The mental health professionals that you may contact at the various hospitals, should you need to, on your own, are:

Lentegeur: John Parker (psychiatrist) – 021 370 1111

Stikland: Liezl Koen (psychiatrist) – 021 940 4400

Valkenberg: Sharon Kleintjes (psychologist) – 021 440 3167

Such services by the abovementioned mental health professionals will not be for the cost of you as participant.

Since this study is related to mental health and takes place at a psychiatric hospital, you need to take note of and consider the fact that the possibility of stigma (people thinking negatively about you for taking part) exists. Carefully consider this when making your decision to take part in the study.

4. POSSIBLE BENEFITS TO PARTICIPANTS AND/OR TO THE SOCIETY

There are no planned personal benefits associated with your participation in this research. The data collected from this study will be used to create a document (questionnaire) in the end with all the right questions about where someone is in their recovery process, specifically for how recovery is understood in the Western Cape and that can be used by those who are interested in recovery.

5. PAYMENT FOR PARTICIPATION

You will not be paid to take part in the study but you will receive an amount of R100,00 for transport costs if you travel to the hospital to take part in this study. Refreshments will be offered to participants at the focus group discussions. There will be no costs involved for you, if you do take part. If you decide to withdraw from the study, you may keep the transport costs that you have already received.

6. PROTECTION OF YOUR INFORMATION, CONFIDENTIALITY AND IDENTITY

Any information you share with me during this study and that could possibly identify you as a participant will be treated as confidential and protected. This will be done by assigning an alias (pseudonym) to you and removing any identifying markers from the information used from the study.

The information received from you may be used in a publication or research thesis or shared with professionals at the hospitals, but your identity or identifying markers will not be revealed. All paper documents containing identifying information and other confidential documentation collected will be stored in a locked cabinet and only my supervisor and I will access to the documents.

All interviews and focus groups will be audio-recorded. The recordings and their transcriptions will be stored under password protection on my laptop and only my supervisor and I will have access to the recordings. If you wish, I can share the transcription of your interview of focus group with you to review. Kindly let me know this during the interview or focus group. I will keep the information on my computer until the data is destroyed after five years.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you agree to take part in this study, you may withdraw at any time without any consequence. You may also refuse to answer any questions you don't want to answer and still remain in the study.

If you are taking part in an interview and want to withdraw from the study, your data from the interview will be withdrawn from any records and analysis, whether electronic or in hard copy format. If you are a focus group participant who wishes to withdraw, you will be able to do so and your answers during the focus group discussion will not be transcribed or will be deleted (redacted) from the transcription, depending on when you withdraw. The audio recording of the transcription can, of course, not be destroyed, because all the other participants' data are part of it, but the audio recording will only be heard by myself and, at most, my supervisor.

8. RESEARCHERS' CONTACT INFORMATION

If you have any questions or concerns about this study, please feel free to contact Anneliese de Wet at 083 564 3471 / anneliesedewet@sun.ac.za and/or the supervisor, Dr Chrisma Pretorius at chrismapretorius@sun.ac.za.

9. RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research participant, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

DECLARATION OF CONSENT BY THE PARTICIPANT

As the participant I confirm that:

- I have read the above information and it is written in a language that I am comfortable with.
- I have had a chance to ask questions and all my questions have been answered.
- All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.

By signing below, I _____ agree to take part in this research study, as conducted by Anneliese de Wet.

_____.....____

Signature of Participant **Date**

DECLARATION BY THE PRINCIPAL INVESTIGATOR

As the **principal investigator,** I hereby declare that the information contained in this document has been thoroughly explained to the participant. I also declare that the participant has been encouraged (and has been given ample time) to ask any questions. In addition I would like to select the following option:

	The conversation with the participant was conducted in a language in which the participant is fluent.
	The conversation with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this "Consent Form" is available to the participant in a language in which the participant is fluent.

_____ _____

Signature of Principal Investigator **Date**

Appendix C27: Informed consent form for carers

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

You are invited to take part in a study conducted by Anneliese de Wet, from the Psychology Department at Stellenbosch University. You were approached as a possible participant because you are:

- a **carer** of a service user (patient) at Lentegeur, Stikland or Valkenberg Hospitals in the Western Cape of South Africa.

1. PURPOSE OF THE STUDY

This study is about mental health recovery.

Recovery is a process to:

- Find meaning and hope in one's life
- Find ways to re-connect with and
- Contribute to one's community even if one is faced by mental health challenges.

The study has two parts to it.

Part 1:

The first part will involve service users, service providers and carers to work out what recovery is and means to these participants and what they think makes recovery work or not.

I want to know these things, to determine what recovery means in the Western Cape and how it is different from how other people in other countries understand recovery.

I plan to ask the participants about these things in individual interviews and focus groups.

Part 2:

The second part of the study will be to create a list of questions from which one will be able to tell where someone is in their recovery process and to involve service users, service providers, carers, psychometrists and academic people who study recovery in South Africa and overseas to help me work out if I am on the right track with these questions. Once I have worked out what the right questions are, I will ask service users at the hospital to answer these questions for me. This will help me to create a document (questionnaire) in the end with all the right questions about where someone is in their recovery process, specifically for how recovery is understood in the Western Cape and that can be used by those who are interested in recovery.

2. WHAT WILL BE ASKED OF ME?

If you agree to take part in this study, you will be asked to either:

- take part in an interview (45 – 60 minutes);
- a focus group discussion (45 - 90 minutes);
- working out the right questions for the document (questionnaire) about recovery.

If you take part in an interview, you might be asked to take part in a focus group discussion later, but you will have the choice to decide whether you want to take part in the focus group or not. The interviews, focus groups and deciding on questions by service users, service providers and carers will take place at either Lentegeur, Stikland or Valkenberg Hospitals at the convenience of the participants involved and will be held in a room at the hospital where the door can be closed to ensure a measure of privacy for participant(s). The other activities for other participants will take place by email.

3. POSSIBLE RISKS AND DISCOMFORTS

It is possible that you might experience feelings of discomfort when talking about mental health recovery in the interviews or focus groups. However, I will ensure that a professional person is available to talk to you about these feelings, should you wish to do so. Please let me know at any point during the interviews or focus groups if you should feel such discomfort and I will pause or stop and first help you to get to the professional person so you can talk to them. The mental health professionals that you may contact at the various hospitals, should you need to are:

Lentegeur: John Parker (psychiatrist) – 021 370 1111

Stikland: Liezl Koen (psychiatrist) – 021 940 4400

Valkenberg: Sharon Kleintjes (psychologist) – 021 440 3167

Such services by the abovementioned mental health professionals will not be for the cost of you as participant.

Since this study is related to mental health and takes place at a psychiatric hospital, you need to take note of and consider the fact that the possibility of stigma (people thinking negatively about you for taking part) exists. Carefully consider this when making your decision to take part in the study.

4. POSSIBLE BENEFITS TO PARTICIPANTS AND/OR TO THE SOCIETY

There are no planned personal benefits associated with your participation in this research. The data collected from this study will be used to create a document (questionnaire) in the end with all the right questions about where someone is in their recovery process, specifically for how recovery is understood in the Western Cape and that can be used by those who are interested in recovery.

5. PAYMENT FOR PARTICIPATION

You will not be paid to take part in the study but you will receive an amount of R100,00 for transport costs if you travel to the hospital to take part in this study. Refreshments will be offered to participants at the focus group discussions. There will be no costs involved for you, if you do take part. If you decide to withdraw from the study, you may keep the transport costs that you have already received.

6. PROTECTION OF YOUR INFORMATION, CONFIDENTIALITY AND IDENTITY

Any information you share with me during this study and that could possibly identify you as a participant will be treated as confidential and protected. This will be done by assigning an alias (pseudonym) to you and removing any identifying markers from the information used from the study.

The information received from you may be used in a publication or research thesis or shared with professionals at the hospitals, but your identity or identifying markers will not be revealed. All paper documents containing identifying information and other confidential documentation collected will be stored in a locked cabinet and only my supervisor and I will access to the documents.

All interviews and focus groups will be audio-recorded. The recordings and their transcriptions will be stored under password protection on my laptop and only my supervisor and I will have access to the recordings. If you wish, I can share the transcription of your interview of focus group with you to review. Kindly let me know this during the interview or focus group. I will keep the information on my computer until the data is destroyed after five years.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you agree to take part in this study, you may withdraw at any time without any consequence. You may also refuse to answer any questions you don't want to answer and still remain in the study.

If you are taking part in an interview and want to withdraw from the study, your data from the interview will be withdrawn from any records and analysis, whether electronic or in hard copy format. If you are a focus group participant who wishes to withdraw, you will be able to do so and your answers during the focus group discussion will not be transcribed or will be deleted (redacted) from the transcription, depending on when you withdraw. The audio recording of the transcription can, of course, not be destroyed, because all the other participants' data are part of it, but the audio recording will only be heard by myself and, at most, my supervisor.

8. RESEARCHERS' CONTACT INFORMATION

If you have any questions or concerns about this study, please feel free to contact Anneliese de Wet at 083 564 3471 / anneliesedewet@sun.ac.za and/or the supervisor, Dr Chrisma Pretorius at chrismapretorius@sun.ac.za.

9. RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research participant, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

DECLARATION OF CONSENT BY THE PARTICIPANT

As the participant I confirm that:

- I have read the above information and it is written in a language that I am comfortable with.
- I have had a chance to ask questions and all my questions have been answered.
- All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.
-

By signing below, I _____ agree to take part in this research study, as conducted by Anneliese de Wet.

_____.....____

Signature of Participant **Date**

DECLARATION BY THE PRINCIPAL INVESTIGATOR

As the **principal investigator,** I hereby declare that the information contained in this document has been thoroughly explained to the participant. I also declare that the participant has been encouraged (and has been given ample time) to ask any questions. In addition I would like to select the following option:

	The conversation with the participant was conducted in a language in which the participant is fluent.
	The conversation with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this "Consent Form" is available to the participant in a language in which the participant is fluent.

_____ _____

Signature of Principal Investigator **Date**

Appendix C28: Informed consent form for service providers

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

You are invited to take part in a study conducted by Anneliese de Wet, from the Psychology Department at Stellenbosch University. You were approached as a possible participant because you are:

- a **service provider** (doctor, nurse, occupational therapist, social worker or assistant to these persons) at Lentegeur, Stikland or Valkenberg Hospitals in the Western Cape of South Africa

1. PURPOSE OF THE STUDY

This study is about mental health recovery.

Recovery is a process to:

- Find meaning and hope in one's life
- Find ways to re-connect with and
- Contribute to one's community even if one is faced by mental health challenges.

The study has two parts to it.

Part 1:

The first part will involve service users, service providers and carers to work out what recovery is and means to these participants and what they think makes recovery work or not.

I want to know these things, to determine what recovery means in the Western Cape and how it is different from how other people in other countries understand recovery.

I plan to ask the participants about these things in individual interviews and focus groups.

Part 2:

The second part of the study will be to create a list of questions from which one will be able to tell where someone is in their recovery process and to involve service users, service providers, carers, psychometrists and academic people who study recovery in South Africa and overseas to help me work out if I am on the right track with these questions. Once I have worked out what the right questions are, I will ask service users at the hospital to answer these questions for me. This will help me to create a document (questionnaire) in the end with all the right questions about where someone is in their recovery process, specifically for how recovery is understood in the Western Cape and that can be used by those who are interested in recovery.

2. WHAT WILL BE ASKED OF ME?

If you agree to take part in this study, you will be asked to either:

- take part in an interview (45 – 60 minutes);
- a focus group discussion (45 - 90 minutes), or
- working out the right questions for the document (questionnaire) about recovery.

If you take part in an interview, you might be asked to take part in a focus group discussion later, but you will have the choice to decide whether you want to take part in the focus group or not. The interviews, focus groups and deciding on questions by service users, service providers and carers will take place at either Lentegeur, Stikland or Valkenberg Hospitals at the convenience of the participants involved and will be held in a room at the hospital where the door can be closed to ensure a measure of privacy for participant(s). The other activities for other participants will take place by email.

3. POSSIBLE RISKS AND DISCOMFORTS

It is possible that you might experience feelings of discomfort when talking about mental health recovery in the interviews or focus groups. However, I will ensure that a professional person is available to talk to you about these feelings, should you wish to do so. Please let me know at any point during the interviews or focus groups if you should feel such discomfort and I will pause or stop and first help you to get to the professional person so you can talk to them. The mental health professionals that you may contact at the various hospitals, should you need to, on your own, are:

Lentegeur: John Parker (psychiatrist) – 021 370 1111

Stikland: Liezl Koen (psychiatrist) – 021 940 4400

Valkenberg: Sharon Kleintjes (psychologist) – 021 440 3167

Such services by the abovementioned mental health professionals will not be for the cost of you as participant.

Since this study is related to mental health and takes place at a psychiatric hospital, you need to take note of and consider the fact that the possibility of stigma (people thinking negatively about you for taking part) exists. Carefully consider this when making your decision to take part in the study.

The risk exists that you may feel compelled to participate because of your work environment. The potential exists that you might think your contribution to the study will negatively affect your employment. Carefully consider this when making your decision to take part in the study.

4. POSSIBLE BENEFITS TO PARTICIPANTS AND/OR TO THE SOCIETY

There are no planned personal benefits associated with your participation in this research. The data collected from this study will be used to create a document (questionnaire) in the end with all the right questions about

where someone is in their recovery process, specifically for how recovery is understood in the Western Cape and that can be used by those who are interested in recovery.

5. PAYMENT FOR PARTICIPATION

You will not be paid to take part in the study. Refreshments will be offered to participants at the focus group discussions. There will be no costs involved for you, if you do take part.

6. PROTECTION OF YOUR INFORMATION, CONFIDENTIALITY AND IDENTITY

Any information you share with me during this study and that could possibly identify you as a participant will be treated as confidential and protected. This will be done by assigning an alias (pseudonym) to you and removing any identifying markers from the information used from the study.

The information received from you may be used in a publication or research thesis or shared with professionals at the hospitals, but your identity or identifying markers will not be revealed. All paper documents containing identifying information and other confidential documentation collected will be stored in a locked cabinet and only my supervisor and I will access to the documents.

All interviews and focus groups will be audio-recorded. The recordings and their transcriptions will be stored under password protection on my laptop and only my supervisor and I will have access to the recordings. If you wish, I can share the transcription of your interview of focus group with you to review. Kindly let me know this during the interview or focus group. I will keep the information on my computer until the data is destroyed after five years.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you agree to take part in this study, you may withdraw at any time without any consequence. You may also refuse to answer any questions you don't want to answer and still remain in the study.

If you are taking part in an interview and want to withdraw from the study, your data from the interview will be withdrawn from any records and analysis, whether electronic or in hard copy format. If you are a focus group participant who wishes to withdraw, you will be able to do so and your answers during the focus group discussion will not be transcribed or will be deleted (redacted) from the transcription, depending on when you withdraw. The audio recording of the transcription can, of course, not be destroyed, because all the other participants' data are part of it, but the audio recording will only be heard by myself and, at most, my supervisor.

8. RESEARCHERS' CONTACT INFORMATION

If you have any questions or concerns about this study, please feel free to contact Anneliese de Wet at 083 564 3471 / anneliesedewet@sun.ac.za and/or the supervisor, Dr Chrisma Pretorius at chrismapretorius@sun.ac.za.

9. RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research participant, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

DECLARATION OF CONSENT BY THE PARTICIPANT

As the participant I confirm that:

- I have read the above information and it is written in a language that I am comfortable with.
- I have had a chance to ask questions and all my questions have been answered.
- All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.

By signing below, I _____ agree to take part in this research study, as conducted by Anneliese de Wet.

_____.....____

Signature of Participant **Date**

DECLARATION BY THE PRINCIPAL INVESTIGATOR

As the **principal investigator,** I hereby declare that the information contained in this document has been thoroughly explained to the participant. I also declare that the participant has been encouraged (and has been given ample time) to ask any questions. In addition I would like to select the following option:

	The conversation with the participant was conducted in a language in which the participant is fluent.

	The conversation with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this "Consent Form" is available to the participant in a language in which the participant is fluent.

_____ _____

Signature of Principal Investigator **Date**

Appendix C29: Informed consent form for professional experts

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

You are invited to take part in a study conducted by Anneliese de Wet, from the Psychology Department at Stellenbosch University. You were approached as a possible participant because you are either:

- a **psychometrist**, or
- a South African or international **recovery scholar**.

1. PURPOSE OF THE STUDY

This study is about mental health recovery.

Recovery is a process to:

- Find meaning and hope in one's life
- Find ways to re-connect with and
- Contribute to one's community even if one is faced by mental health challenges.

The study has two parts to it.

Part 1:

The first part will involve service users, service providers and carers to work out what recovery is and means to these participants and what they think makes recovery work or not.

I want to know these things, to determine what recovery means in the Western Cape and how it is different from how other people in other countries understand recovery.

I plan to ask the participants about these things in individual interviews and focus groups.

Part 2:

The second part of the study will be to create a list of questions from which one will be able to tell where someone is in their recovery process and to involve service users, service providers, carers, psychometrists and academic people who study recovery in South Africa and overseas to help me work out if I am on the right track with these questions. Once I have worked out what the right questions are, I will ask service users at the hospital to answer these questions for me. This will help me to create a document (questionnaire) in the end with all the right questions about where someone is in their recovery process, specifically for how recovery is understood in the Western Cape and that can be used by those who are interested in recovery.

2. WHAT WILL BE ASKED OF ME?

If you agree to take part in this study, you will be asked to assist in working out the right questions for the document (questionnaire) about recovery. The activities, that you will be requested to take part in, will take place by email.

3. POSSIBLE RISKS AND DISCOMFORTS

It is not anticipated that you will experience feelings of discomfort when taking part in this study.

The risk exists that you may feel compelled to participate because of your involvement in this field of study or work. The potential exists that you might think your contribution to the study is demanded. Carefully consider this when making your decision to take part in the study. This is not the intent of the principal investigator. You are free to decide to take part or not.

4. POSSIBLE BENEFITS TO PARTICIPANTS AND/OR TO THE SOCIETY

There are no planned personal benefits associated with your participation in this research. The data collected from this study will be used to create a document (questionnaire) in the end with all the right questions about where someone is in their recovery process, specifically for how recovery is understood in the Western Cape and that can be used by those who are interested in recovery.

5. PAYMENT FOR PARTICIPATION

You will not be paid to take part in the study. There should be no costs involved for you.

6. PROTECTION OF YOUR INFORMATION, CONFIDENTIALITY AND IDENTITY

Any information you share with me during this study and that could possibly identify you as a participant will be treated as confidential and protected. This will be done by assigning an alias (pseudonym) to you and removing any identifying markers from the information used from the study.

The information received from you may be used in a publication or research thesis or shared with professionals at the hospitals, but your identity or identifying markers will not be revealed. All paper documents containing identifying information and other confidential documentation collected will be stored in a locked cabinet and only my supervisor and I will access to the documents.

All data will be stored under password protection on my laptop. I will keep the data on my computer until the data are destroyed after five years.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you agree to take part in this study, you may withdraw at any time without any consequence. You may also refuse to answer any questions you don't want to answer and still remain in the study.

8. RESEARCHERS' CONTACT INFORMATION

If you have any questions or concerns about this study, please feel free to contact Anneliese de Wet at +27 83 564 3471 / anneliesedewet@sun.ac.za and/or the supervisor, Dr Chrisma Pretorius at chrismapretorius@sun.ac.za.

9. RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research participant, contact Ms Maléne Fouché [mfouche@sun.ac.za; +27 21 808 4622] at the Division for Research Development.

DECLARATION OF CONSENT BY THE PARTICIPANT

As the participant I confirm that:

- I have read the above information and it is written in a language that I am comfortable with.
- I have had a chance to ask questions and all my questions have been answered.
- All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.

By signing below, I _____ agree to take part in this research study, as conducted by Anneliese de Wet.

_____.....____

Signature of Participant **Date**

DECLARATION BY THE PRINCIPAL INVESTIGATOR

As the **principal investigator,** I hereby declare that the information contained in this document has been thoroughly explained to the participant. I also declare that the participant has been encouraged (and has been given ample time) to ask any questions. In addition I would like to select the following option:

	The conversation with the participant was conducted in a language in which the participant is fluent.
	The conversation with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this "Consent Form" is available to the participant in a language in which the participant is fluent.

_____ _____

Signature of Principal Investigator **Date**

Appendix C30: Consent to use RAS

From: **Patrick Corrigan** corrigan@iit.edu
Subject: Re: [Ext] Re: Recovery Assessment Scale - reproduction permission please
Date: 11 September 2020 at 17:18
To: De Wet, A, Mej [anneliesedewet@sun.ac.za] anneliesedewet@sun.ac.za

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you have my permission
Pat

Patrick Corrigan
Distinguished Professor and
Associate Chairperson for Research
Department of Psychology
Illinois Institute of Technology
3424 S State St
Chicago, IL 60616
312 567-6751
pronouns: he, him, his

National Consortium on Stigma and Empowerment www.ncse1.org
Honest, Open, Proud program www.HOPprogram.org
Chicago Health Disparities Center www.chicagohealthdisparities.org

Stigma and Health Journal www.apa.org/pubs/journals/sah/

On Fri, Sep 11, 2020 at 10:05 AM De Wet, A, Mej [anneliesedewet@sun.ac.za] <anneliesedewet@sun.ac.za> wrote:

> Dear Pat,
>
> I refer to my email lat year regarding the use of the Recovery Assessment Scale in my PhD research. You gave me the permission, as per below. However, I want to make sure that it is in order for me to reproduce the RAS in my dissertation. Would you be able to give me permission to do so please?
>
> Thank you.
>
> Kindest regards,
> Anneliese
>
> > On 28 Aug 2019, at 13:14, Patrick Corrigan <corrigan@iit.edu> wrote:
> >
> > You have my permsision
> >
> > Pat
> >
> > Patrick W. Corrigan
> > Distinguished Professor of Psychology
> > Illinois Institute of Technology
> > 01 312 567-6751
> > Pronouns: he, him, his
> >
> > National Consortium on Stigma and Empowerment (www.NCSE1.org)
> > Honest, Open, Proud Program (www.HOPprogram.org)
> > *Stigma and Health*, an APA Journal (http://www.apa.org/pubs/journals/sah/index.aspx)
> >
> > Chicago Health Disparities Center (www.chicagohealthdisparities.org)
> >
> > **From:** De Wet, A, Mej [anneliesedewet@sun.ac.za] <anneliesedewet@sun.ac.za>
> > **Sent:** Wednesday, August 28, 2019 4:27 AM
> > **To:** Patrick Corrigan <corrigan@iit.edu>
> > **Cc:** Carla Kundert <ckundert@iit.edu>
> > **Subject:** Re: Recovery Assessment Scale - 1995 publication by Giffort et al
> >
> > Dear Prof Corrigan,
> >
> > I have not been able to find any contact details for Daniel W Giffort, though I have searched quite widely. I have been in contact with Dr Nicola Hancock of Sydney University (and we are planning in fact to meet up at the Refocus on Recovery conference in Nottingham next week) and she said that, when

she developed the RAS-DS, she received an approval of some sorts from you to use the original RAS.

Is it possible to give me some form of permission too, to use it in my research please?

Sorry to be a bother again!

Kindest regards,
Anneliese

ANNELIESE DE WET
BComm LLB, MA (Psych) (US)
Psychology Department
Stellenbosch University
+27 83 564 3471

On 25 Aug 2019, at 18:57, Patrick Corrigan <corrigan@iit.edu> wrote:

Carla
Can we talk tomorrow about how to fill publication request

Pat

Patrick W. Corrigan
Distinguished Professor of Psychology
Illinois Institute of Technology
01 312 567-6751
Pronouns: he, him, his

National Consortium on Stigma and Empowerment (www.NCSE1.org)
Honest, Open, Proud Program (www.HOPprogram.org)
Stigma and Health, an APA Journal (http://www.apa.org/pubs/journals/sah/index.aspx)

Chicago Health Disparities Center (www.chicagohealthdisparities.org)

From: De Wet, A, Mej [anneliesedewet@sun.ac.za] <anneliesedewet@sun.ac.za>
Sent: Sunday, August 25, 2019 10:36 AM
To: corrigan@iit.edu
Subject: Fwd: Recovery Assessment Scale - 1995 publication by Giffort et al

Dear Prof Corrigan,

I sent the email below a few weeks ago and was wondering whether you are perhaps able to reply to me when you have a moment.

Thank you so much and sorry to be such a bother!

Kindest regards,
Anneliese

ANNELIESE DE WET
BComm LLB, MA (Psych) (US)
Psychology Department
Stellenbosch University
+27 83 564 3471

Begin forwarded message:

Appendix C31: Consent to use RAS-DS

From: **Nicola Hancock** nicola.hancock@sydney.edu.au
Subject: RE: RAS-DS
Date: 12 September 2020 at 01:54
To: De Wet, A, Mej [anneliesedewet@sun.ac.za] anneliesedewet@sun.ac.za

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Of course Anneliese, you are very welcome to include it in your appendices. I am delighted to hear you are at the point of pulling the thesis together!
All the best
Nic

Associate Professor Nicola Hancock, PhD
Lead, Mental Health Stream, Centre for Disability Research and Policy (CDRP)
The University of Sydney
Occupational Therapy | Faculty of Medicine and Health
+61 2 9351 9379 | +61 425 254 306
Staff website: http://sydney.edu.au/health-sciences/about/people/profiles/nicola.hancock.php
CDRP website: https://sydney.edu.au/medicine-health/our-research/research-centres/centre-for-disability-research-and-policy.html
https://orcid.org/0000-0002-6877-9239

From: De Wet, A, Mej [anneliesedewet@sun.ac.za] <anneliesedewet@sun.ac.za>
Sent: Saturday, 12 September 2020 12:47 AM
To: Nicola Hancock <nicola.hancock@sydney.edu.au>
Subject: Re: RAS-DS

Dear Nicola,

I hope you are well.

I want to ask whether you can give me permission to reproduce the RAS-DS as part of my dissertation. I need to include it as an appendix for the examinars to be able to refer to. Would that be possible please?

Thanks so much for considering my request.

Kindest regards,
Anneliese

On 26 Aug 2019, at 00:31, Nicola Hancock <nicola.hancock@sydney.edu.au> wrote:

Dear Anneliese
You are very welcome to use the RAS-DS. You might be interested to know that a team of therapists/researchers at Valkenberg Hospital and University of Cape Town are using the RAS-DS. Last time I spoke to them, they were exploring the possibility of developing a modified version relevant to particular communities understanding of recovery.
All the best with your study.
Warm regards
Nicola

Nicola Hancock PhD
Senior Lecturer | Post-Graduate Coordinator Disability and Mental Health Research

The University of Sydney
Occupational Therapy | Faculty of Health Sciences
+61 2 9351 9379 | +61 425 254 306
http://sydney.edu.au/health-sciences/about/people/profiles/nicola.hancock.php
<image001.png> https://orcid.org/0000-0002-6877-9239

<image002.jpg>

From: De Wet, A, Mej [anneliesedewet@sun.ac.za] <anneliesedewet@sun.ac.za>
Sent: Monday, 26 August 2019 3:43 AM
To: Nicola Hancock <nicola.hancock@sydney.edu.au>
Subject: RAS-DS

Dear Dr Hancock,

I am a PhD candidate at Stellenbosch University in South Africa. As part of my PhD, I am developing a recovery measure/instrument/scale for our context. I have read much on the RAS-DS scale and would like to have access to it, in order to use it as a basis (together with some other recovery scales) to develop a scale for our context. Thank you for making it so accessible to other researchers.

Would you perhaps be able to provide me with permission to use the scale please? I will not be adapting your scale, but merely using it to inform items that I will be developing for the scale in our context. I would appreciate it, since it would help me proceed in my study.

Thank you very much!

Kindest regards,
Anneliese
ANNELIESE DE WET
BComm LLB, MA (Psych) (US)
Psychology Department
Stellenbosch University
+27 83 564 3471

Appendix C32: Consent to use QPR

From: **Sandra Neil** Sandra.Neil@gmmh.nhs.uk
Subject: Re: The questionnaire about the process of recovery (QPR)
Date: 11 September 2020 at 20:50
To: De Wet, A, Mej [anneliesedewet@sun.ac.za] anneliesedewet@sun.ac.za

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Hi Anneliese

Yes of course that's fine

kind regards,
Sandra

From: De Wet, A, Mej [anneliesedewet@sun.ac.za] <anneliesedewet@sun.ac.za>
Sent: Friday, September 11, 2020 4:09 PM
To: Sandra Neil <Sandra.Neil@gmmh.nhs.uk>
Subject: [EXTERNAL] Re: The questionnaire about the process of recovery (QPR)

[External Email – This Email has come from outside GMMH. Do not click any links or open attachments if the sender is not known and trusted]

Dear Sandra,

I contacted you last year for permission to use the QPR in my PhD research, as per the emails below. I just wanted to add to it and ask whether you would provide me with permission to reproduce the QPR in the appendices of my dissertation? The examiners would need to be able to refer to it, if they feel the need.

Thank you for considering my additional request.

Kindest regards,
Anneliese

On 28 Aug 2019, at 09:17, Sandra Neil <Sandra.Neil@gmmh.nhs.uk> wrote:

Hi Anneliese

Yes we are happy for you to use the QPR.

Kind regards
Sandra

Dr Sandra Neil
Clinical Psychologist / PIDS Team Coordinator
Cromwell House CMHT
Cromwell Road
Manchester
M30 0GT

0161 358 1280

From: De Wet, A, Mej [anneliesedewet@sun.ac.za] <anneliesedewet@sun.ac.za>
Sent: 25 August 2019 18:19
To: Sandra Neil <Sandra.Neil@gmmh.nhs.uk>
Subject: [EXTERNAL] The questionnaire about the process of recovery (QPR)

[External Email - This Email has come from outside GMMH. Do not click any links or open attachments if the sender is not known and trusted]

Dear Dr Neil,

I am a PhD candidate at Stellenbosch University in South Africa. As part of my PhD, I am developing a recovery measure/instrument/scale for our context. I have read much on the QPR scale and would like to have access to it, in order to use it as a basis (together with some other recovery scales) to develop a scale for our context.

Would you perhaps be able to provide me with permission to use the scale please? I would appreciate it, since it would help me proceed in my study.

Thank you very much!

Kindest regards,
Anneliese
ANNELIESE DE WET
BComm LLB, MA (Psych) (US)
Psychology Department
Stellenbosch University
+27 83 564 3471

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Greater Manchester Mental Health NHS Foundation Trust

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Remember that emails sent or received by our staff may be subject to disclosure under the Freedom of Information Act.

Greater Manchester Mental Health NHS Foundation Trust

Appendix C33: Consent to use MARS

From: **Medoff, Deborah** Dmedoff@som.umaryland.edu
Subject: Re: Maryland Assessment of Recovery in people with Serious mental illness (MARS)
Date: 11 September 2019 at 13:29
To: De Wet, A, Mej [anneliesedewet@sun.ac.za] anneliesedewet@sun.ac.za

Sorry you didnt get a reply. This is the first I have received. The scale is in the public domain and you are free to use it. The items are in the latest publication, but I will send you a copy when I am at my office.

Deb

Get Outlook for Android

From: De Wet, A, Mej [anneliesedewet@sun.ac.za] <anneliesedewet@sun.ac.za>
Sent: Wednesday, September 11, 2019 6:41:16 AM
To: Medoff, Deborah <Dmedoff@som.umaryland.edu>
Subject: Re: Maryland Assessment of Recovery in people with Serious mental illness (MARS)

Dear Dr Medoff,

I am not sure whether you received my email below, but if so, could I ask for your reply please?

Thank you so much!

Kindest regards,
Anneliese

ANNELIESE DE WET
BComm LLB, MA (Psych) (US)
Psychology Department
Stellenbosch University
SOUTH AFRICA
+27 83 564 3471

> On 28 Aug 2019, at 19:01, De Wet, A, Mej [anneliesedewet@sun.ac.za] <anneliesedewet@sun.ac.za> wrote:
>
> Dear Dr Medoff,
>
> I am a PhD candidate at Stellenbosch University in South Africa. As part of my PhD, I am developing a recovery measure/instrument/scale for our context. I have read much on the MARS recovery scale and would like to have access to it, in order to develop a scale for our context. However, I cannot find a copy of the actual MARS scale online. I have also tried contacting Drs Drapalski and Dixon, but have not had a response from them yet.
>
> Would you perhaps be able to share a copy of the scale with me please? I would also like to obtain permission to use it in my research, if that is possible, please. I would appreciate your assistance with this, it would help me proceed in my study.
>
> Thank you very much!
>
> Kindest regards,
> Anneliese
>
> **ANNELIESE DE WET**
> BComm LLB, MA (Psych) (US)
> Psychology Department
> Stellenbosch University
> +27 83 564 3471

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Manuscript title Perceptions and Understanding of Mental Health Recovery for Service Users, Carers and Service Providers: A South African Perspective

Author names (in order of authorship) Anneliese de Wet and Chrisma Pretorius

Corresponding author Anneliese de Wet **Phone number** +27835643471

Email address anneliese.dewet@gmail.com **APA publication** Psychiatric Rehabilitation Journal

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Appendix H1: Letter of confirmation of professional editing

On Track Editing and Proofreading

8 September 2020

In my professional capacity as an academic English language and technical editor, I can confirm that the submitted PhD dissertation, authored by Anneliese de Wet, has been professionally language edited, the document structure correctly formatted, citations and references cross-checked, and the citations and references formatted according to APA 7th edition specifications.

Title of PhD dissertation:

THE DEVELOPMENT OF A CONTEXTUALLY APPROPRIATE MEASURE OF INDIVIDUAL RECOVERY FOR MENTAL HEALTH SERVICE USERS IN THE SOUTH AFRICAN CONTEXT

Kind regards

Jacqueline Gamble

http://www.ontrackediting.co.za/index.html